

# Quality of care in head and neck oncology

Development of a nationwide instrument



Lydia F.J. van Overveld

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The research presented in this thesis was conducted at IQ healthcare. This department is part of the Radboud Institute for Health Sciences (RIHS), one of the approved research institutes of the Radboud university medical center, Nijmegen, the Netherlands.

Financial support by the Radboud University for the publication of this thesis is gratefully acknowledged. The study was financially supported by the Dutch Association of University Medical Centers (NFU) in the project 'kwaliteitsregistratie in de keten' (2013-2016) in tight cooperation with CZ health insurer.

ISBN: 978-94-6332-303-1

Cover design: GVO drukkers & vormgevers B.V.

Lay out : Lydia van Overveld

Print: GVO drukkers & vormgevers B.V.

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# **Quality of care in head and neck oncology**

## **Development of a nationwide instrument**

### **Proefschrift**

ter verkrijging van de graad van doctor  
aan de Radboud Universiteit Nijmegen  
op gezag van de rector magnificus prof. dr. J.H.J.M. van Krieken,  
volgens besluit van het college van decanen  
in het openbaar te verdedigen op woensdag 28 februari 2018  
om 14.30 uur precies

door

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te Bergen op Zoom

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# CHAPTER 1

## General introduction





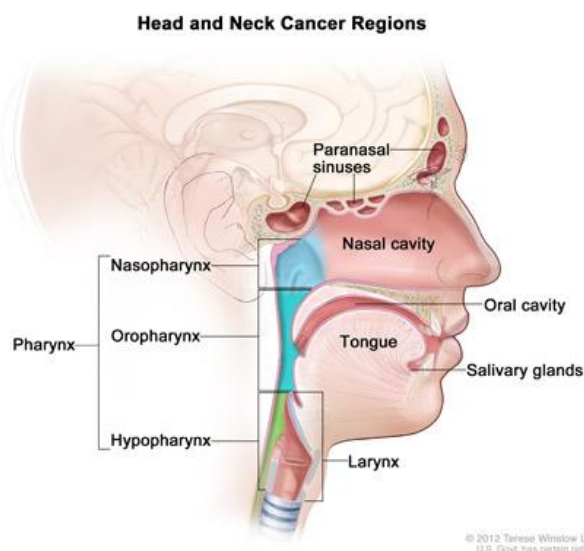
## BACKGROUND

This thesis describes studies on the development of a multidisciplinary quality registration for patients with head and neck cancer (HNC) in the Netherlands; the Dutch Head and Neck Audit (DHNA). It also describes the first results of the DHNA, the evaluation of the indicators and preferences for audit and feedback.

## HEAD AND NECK CANCER

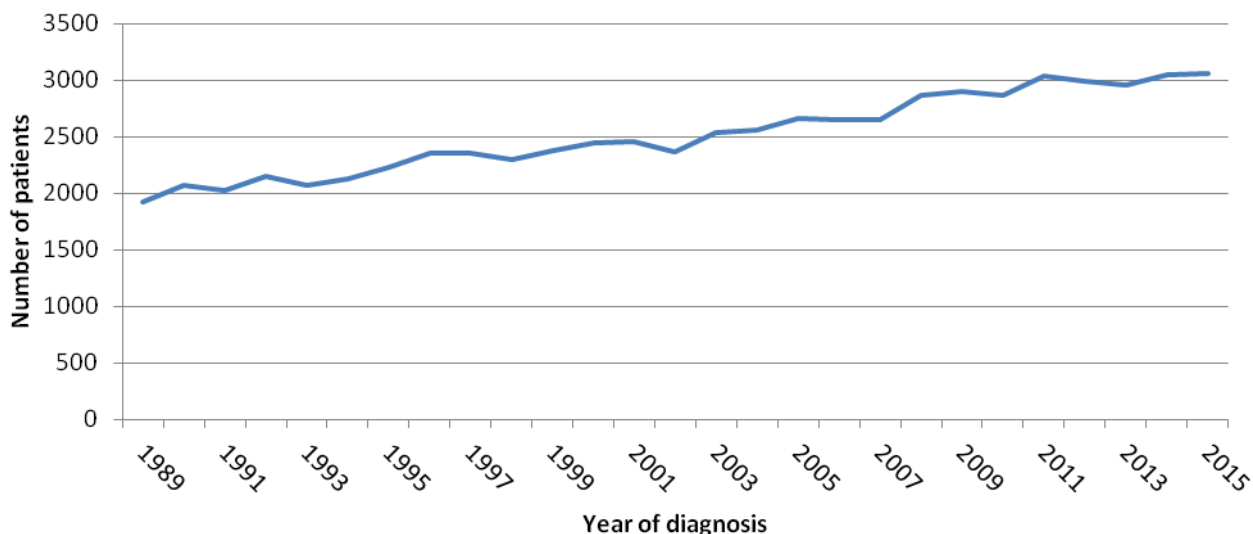
### Incidence and survival

Head and neck cancer (HNC) represents a heterogeneous group of predominantly epithelial malignancies that arise in the paranasal sinuses, nasal cavity and nasopharynx, oral cavity, oropharynx, hypopharynx, larynx, and salivary glands (Figure 1)<sup>1</sup>. Histologically, squamous cell carcinoma is the most important subtype<sup>2,3</sup>.

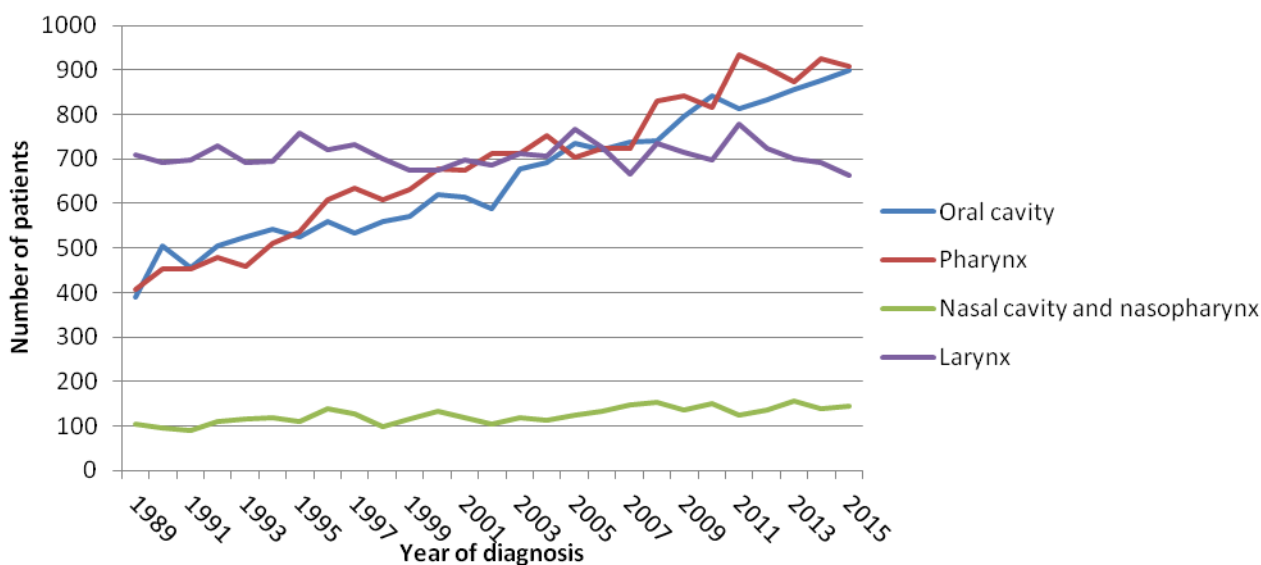


**Figure 1.** Head and neck cancer sites. Reprinted from *National Cancer Institute (NCI)* website, by NCI, 2012<sup>1</sup>.

Overall, HNC accounts for more than 500,000 cases annually worldwide<sup>4,5</sup>. In the Netherlands, approximately 3000 patients are yearly diagnosed (Figure 2)<sup>6</sup>. It was the 9<sup>th</sup> most common cancer in women and the 7<sup>th</sup> in men in 2016<sup>6</sup>. When incidence rates are subdivided for different sites, especially oral cavity and oropharynx have shown an increase in incidence (Figure 3)<sup>6</sup>. A worldwide increase in incidence of oropharyngeal cancer also has been noted in a large study from a database of five continents<sup>7</sup>, especially in young adults in the USA and European countries<sup>2,7</sup>.

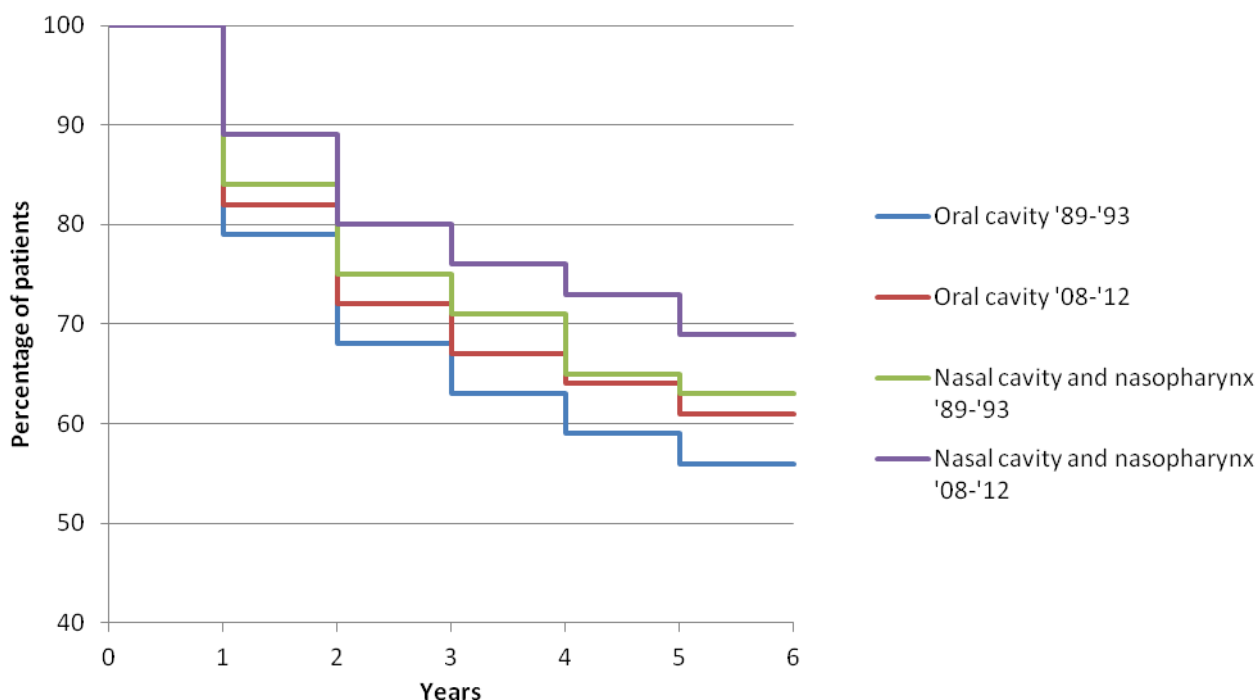


**Figure 2.** Number of new patients with head and neck cancer between 1990 and 2015 in the Netherlands. Data retrieved from *Figures on cancer (Cijfers over kanker)* website, by the Netherlands Comprehensive Cancer Organisation (IKNL), 2017<sup>6</sup>.



**Figure 3.** Number of new patients with one of four subsites of head and neck cancer between 1990 and 2015 in the Netherlands. Data retrieved from *Figures on cancer (Cijfers over kanker)* website, by the Netherlands Comprehensive Cancer Organisation (IKNL), 2017<sup>6</sup>.

Figure 4 shows that the 5-year survival of patients diagnosed with HNC in the oral cavity, nasal cavity and nasopharynx, increased over time in the Netherlands. In addition, a Dutch study with 13,106 patients showed that 5 year survival for patients with oral cavity cancer improved from 57% in 1991-1995 to 62% in 2006-2010<sup>8</sup>.



**Figure 4.** Survival of patients diagnosed with HNC in the oral cavity and nasal cavity and nasopharynx between 1989-1993 and 2008-2012 in the Netherlands. Data retrieved from *Figures on cancer (Cijfers over kanker)* website, by the Netherlands Comprehensive Cancer Organisation (IKNL), 2017<sup>6</sup>.

## Symptoms, risk factors and treatment

HNC has significant impact on a patient's well being as HNCs grow relatively aggressive in an anatomically and functionally important area<sup>2,9,10</sup>. During and after treatment, patients often experience problems with speech, swallowing, and physical disfigurement due to toxicity and side effects<sup>11-15</sup>. In addition, they often suffer from psychological disorders, such as depression and anxiety, and social problems, such as relationship difficulties with their partner and family members, and loss of work<sup>16-18</sup>. The median age for diagnosis is in a patient's early 60s, with a male predominance<sup>2,19,20</sup>.

The most important risk factors are tobacco and alcohol consumption<sup>2,21-23</sup>. Wyss et al. reported that among never cigarette smokers, the HNC risk increased in ever cigar smokers (Odds Ratio (OR): 2.54 (95% confidence interval (CI): 1.93, 3.34)) and ever pipe smokers (OR: 2.08 (95% CI: 1.55-2.81)). These ORs increased with increasing frequency and duration of smoking ( $P_{\text{trend}} \leq 0.0001$ )<sup>24</sup>. Regarding alcohol: alcohol consumption was associated with an increased risk of HNC (RR: 2.74 (95% CI: 1.85-4.06) for those drinking  $\geq 30$  g ethanol/day (about three or more drinks) as compared with abstainers<sup>21,25,26</sup>.

In addition, Human Papillomavirus (HPV) has been reported as an important etiological factor, especially for oropharyngeal cancer (OPC)<sup>27</sup>. A meta-analysis which included studies that were published between 2002-2012 showed a prevalence of HPV of any type in patients with HNC in European countries of 40% (95% CI; 34.6% to 45.5%), whereas the prevalence was 41.3% (95% CI; 31.8% to 50.7%) for OPC<sup>28</sup>. Apparently, rates of HPV-related OPC have been rapidly

rising in Western countries while the incidence of alcohol- and smoking-related tumours has decreased and a majority of non-smokers and non-drinkers are affected by HPV-related disease in OPC<sup>29,30</sup>. In addition, research showed a difference in impact of HPV and smoking for both men and women: HPV has a greater impact on OPC incidence trends for men, in contrast to smoking for women<sup>27</sup>. In contrast, a Dutch study concluded that even in the subset of OPC, HPV did not appear to be the main contributor to a rising incidence of OPC and smoking and alcohol consumption continue to play a role<sup>31</sup>.

## Need for standard of care

A multidisciplinary approach is required for optimal diagnostics and decision making around treatment, treatment planning, and post treatment response assessment. Structured multidisciplinary care plans which detail essential steps in the care of patients were developed<sup>32</sup>. A multidisciplinary approach includes the input from surgeons, medical oncologists, radiation oncologists, and pathologists as well as supportive care givers such as dentists, speech and swallowing therapists, dieticians, physiotherapists, oral hygienists and rehabilitation therapists. HNC is treated with surgery, systemic therapy, radiation or a combination of these. A strategy for better coordination of services across the entire care continuum with alignment and collaboration of all disciplines is required for patients with HNC<sup>33</sup>. In other words: integrated care is crucial<sup>34,35</sup>. Integrated care is not only crucial for HNC, but is of great value for other oncologic diseases as well<sup>36,37</sup>.

In the Netherlands, HNC care is centralized in 14 hospitals: eight Head and Neck Oncology Centres (HNOCs) and six affiliated centres (Figure 5)<sup>38</sup>. The affiliated centres have committed themselves to using the same treatment protocols as the related HNOC. The various medical specialists and allied health professionals involved in HNC care are united in two national foundations, one for medical specialists (NWHHT)<sup>a</sup> and one for allied health professionals (PWHHT)<sup>b</sup>. There is also the Dutch Patient Association 'Patiëntenvereniging Hoofd-hals'<sup>39</sup>. Even with these specialized hospitals and foundations, optimal care for HNC patients remains complex.

**Figure 5.** The fourteen specialized hospitals in head and neck cancer care in the Netherlands. Red = Head and Neck Oncology Centres, blue = affiliated centres.



<sup>a</sup> Dutch Head and Neck Society

<sup>b</sup> Dutch Head and Neck Allied Health Professionals Group

## QUALITY OF CARE

Now that the survival for patients with HNC improved during the last decades, there are opportunities to shift focus. Besides focusing on survival, more focus could be directed towards quality of healthcare, including quality of life. The WHO stated already in 2006 that, even when healthcare systems are well developed and resourced, variation in quality of care remains a serious concern<sup>40</sup>. Therefore, it is important to gain insight into the care that is actually provided in order to monitor and effectively improve high-quality integrated care<sup>41,42</sup>. By measuring the quality of care in a broad spectrum, hospitals are able to identify those aspects of healthcare that may need improvement. Similar initiatives already show large beneficial effects of measuring quality of care. For example, the Dutch Surgical Colorectal Audit (DSCA) that measures the quality of care of patients with colon carcinomas. They show that transparency and giving feedback results in increased guideline compliance and a reduction of complication-, re-intervention and postoperative mortality rates<sup>43</sup>.

### Quality indicators

To measure and monitor quality of care, a dashboard of valid and reliable Quality Indicators (QIs) can be used<sup>44,45</sup>. A definition of a quality indicator was already given in 1988 by Donabedian; "a measurable element of practice performance for which there is evidence or consensus that it can be used to assess the quality of care"<sup>42</sup>. QIs infer a judgement about quality of care provided<sup>44</sup>. They can refer to outcomes, structures, or processes of care<sup>44</sup>. Process and outcome indicators are measured on patient level, structure indicators are measured on hospital level. An example of a process indicator is if the patient is discussed in a multidisciplinary team meeting. An example of an outcome indicator is the survival of patients or patients quality of life and patients' experiences. The latter can be assessed with questionnaires regarding Patient Reported Outcomes (PROMs) or Experiences (PREMs). An example of a structure indicator is the presence of case manager/oncology nurse for a minimum of four days a week.

Process and outcome indicators are calculated by dividing the numerator (the total number of patients who received the predefined measurable element of practice performance or that met the experience) by the denominator (the total number of patients who needed to receive the predefined measurable element of practice performance or to experience the outcome) (Figure 6). A structure indicator is often expressed as a percentage of hospitals that meet the indicator.

$$\% \text{ Compliance} = \frac{\text{Numerator}}{\text{Denominator}} \times 100\%$$

**Figure 6.** Calculation of a process and outcome indicator.

## **The problem: measuring quality of integrated head and neck cancer care**

An often used method to improve integrated quality of care, is by measuring indicators. Unfortunately, there is no set of indicators that measures the quality of integrated HNC care along the entire pathway, from referral to follow-up. Published indicator sets to measure quality in HNC care only incorporate treatment aspects<sup>46</sup>. In another publication, the care delivered by allied health professionals is not included<sup>47</sup>. Since HNC care is classified as integrated care where alignment and collaboration of several disciplines is crucial, quality of care should be measured within the entire healthcare process. Herewith, we can assure that quality of healthcare will be measured and can be improved if necessary.

### ***Including patients' need and preferences***

Nowadays, providing patient-centred care is an essential component of high quality integrated care<sup>48</sup>. Responding to the needs and preferences of patients is an important aspect of current healthcare policy worldwide<sup>49,50</sup>. It leads to positive clinical outcomes and increased patient satisfaction<sup>48,49,51-53</sup>. As a result, increased patient satisfaction might result in a better adherence to treatment recommendations and increase quality of life<sup>54</sup>. Unfortunately, information on patients' needs and preferences for integrated care is lacking.

To improve the quality of integrated HNC care, it is crucial to develop a comprehensive set of quality indicators from different perspectives to incorporate all crucial aspects of HNC care. Furthermore, the perspective of the patient, by taking PROMs, PREMS and patients' needs and preferences into account, should be included by all means.

## **The method: quality registration**

A quality registration is an independent data collection tool to assess the quality of care<sup>55</sup>. A quality registration gives insight in the quality of care and can therefore be used to monitor and effectively improve quality of care. Existing quality registrations already showed improvements in healthcare, for example decreased complication and mortality rates<sup>43,56</sup>.

Examples of quality registrations in the Netherlands are the Dutch Surgical Colorectal Audit (DSCA) or the National Registration Orthopedic Implants (LROI)<sup>57,58</sup>. Many oncological registries are included in the Dutch Institute for Clinical Auditing (DICA). This is a national organization that gives insight in the quality of care with reliable comparisons and analysis.

According to the website of the National Institute for Public Health and Environment (RIVM), there are currently 181 active quality registrations and annual costs for quality registrations are estimated on 80 million<sup>55</sup>. This amount is at the expense of the provision of care. Therefore, quoted by the director of the Dutch Hospital Association (NVZ), it is important to significantly reduce the registrations and to make quality registrations as comprehensive as possible.

## ***Audit and feedback***

After measuring the quality of care via a quality registration, feedback should be given on the results to the healthcare professionals in order to improve professional practice and outcomes in healthcare<sup>59,60</sup>. Audit and feedback is defined as any summary of clinical performance of healthcare over a specified period of time, given in a written, electronic or verbal format, offering professionals performance information and motivation to improve<sup>61</sup>.

The last decade, much effort is devoted to improve professional practice and outcomes in healthcare using audit and feedback, unfortunately with varying effects<sup>60</sup>. In addition, implementation of audit and feedback is likely to be more effective when feedback messages can influence barriers to change behaviour. These barriers appear to differ across individuals<sup>62</sup>. In addition, stakeholders have different perspectives on quality of care<sup>44</sup>. For example, patients often emphasize good communication skills, whereas healthcare professionals have more interest in oncologic outcomes, for example survival and recurrence of the cancer<sup>44</sup>. Health insurers, who search for quality information suitable to explore differences in quality of care as a basis for their contracting, are an important stakeholder as well. Therefore, in an integrated pathway, it seems likely to give personalized feedback to all stakeholders: to healthcare professionals, as well as to patients and health insurers.

Unfortunately, little is known about how each stakeholder prefers to receive feedback. To set up an effective quality registration, it is crucial to unveil these unknown preferences of receiving feedback.

## **MAIN OBJECTIVES**

The main objectives of this thesis are:

1. To develop a comprehensive and evidence based set of quality indicators from three different perspectives: medical specialists, allied health professionals and patients;
2. To investigate the preferences of various stakeholders on receiving audit and feedback.

## **THESIS OUTLINE**

In order to measure the quality of multidisciplinary integrated HNC care, a comprehensive and evidence based set of quality indicators from three different perspectives was developed. The development of indicators from the perspective of the medical specialists and the allied health professionals is described in **Chapter 2**. The development of indicators from the perspective of the patient, by investigating patients' needs and preferences, is described in **Chapter 3**.

The results of the first quality measurements regarding the quality of care delivered by medical specialists and allied health professionals are presented in **Chapter 4**. The first results regarding patients quality of life and the patients' experiences in HNC care are presented in **Chapter 5**.

In order to increase the effectiveness of feedback, we investigated the preferences of various stakeholders on receiving audit and feedback (**Chapter 6**). We hypothesize that adapting feedback to the preferences of these different stakeholders, will improve their response to the information delivered and that more improvement effects of audit and feedback could be observed.

The main findings of this thesis together with the methodological considerations, and implications for clinical practice, further research and policy making will be outlined in **Chapter 7**.

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## CHAPTER 2

### Quality indicators of integrated care for patients with head and neck cancer



Lydia F.J. van Overveld, Jozé C.C. Braspenning and Rosella P.M.G. Hermens

Clinical Otolaryngology. 2017; 42(2): 322-329

## **ABSTRACT**

**Objectives:** Oncological care is very complex, and delivery of integrated care with optimal alignment and collaboration of several disciplines is crucial. To monitor and effectively improve high-quality integrated oncological care, a dashboard of valid and reliable quality indicators (QIs) is indispensable. The aim was to develop multidisciplinary QIs to measure quality of integrated oncological care, specifically for head and neck cancer (HNC) patients.

**Design:** The RAND-modified Delphi method was used to decide on the outcome, process, and structure QIs from three different perspectives. In addition, case-mix factors were determined.

**Setting:** Integrated HNC care hospitals in the Netherlands.

**Participants:** HNC patients, chairmen of both patient organisations, and medical specialists and allied health professionals involved in HNC care in the Netherlands.

**Main outcome measures:** Outcome, process, and structure indicators.

**Results:** Outcome indicators were assigned to healthcare status, tumour recurrence, complications, quality of life, and patient experiences. The process indicators focused on the (allied health) care aspects during the diagnostic, treatment, and follow-up phases; for example, regarding waiting times, multidisciplinary team meetings, and screening for the need of allied healthcare.

**Conclusions:** This is the first set of multidisciplinary QIs for HNC care, to assess quality of integrated care agreed by patients and professionals. This set can be used to build other oncological quality dashboards for integrated care.

## INTRODUCTION

The delivery of high-quality oncological integrated care, with optimal alignment and collaboration of all disciplines involved throughout the entire healthcare process, is crucial for patients<sup>1,2</sup>. However, management of integrated care is very complex<sup>1,3</sup>. To monitor and effectively improve high-quality integrated care, a dashboard of valid and reliable quality indicators (QIs) is indispensable<sup>4,5</sup>.

Unfortunately, little is known about QIs in oncological integrated care. Many QIs are developed for oncological diseases, although often only for a single part of the healthcare process; for example, the multidisciplinary team meeting (MTM) or surgery<sup>6-8</sup>. Moreover, indicator sets in oncology do not incorporate the care delivered by allied health professionals (AHPs)<sup>9,10</sup> who play an important role in the care delivered<sup>11,12</sup>.

For patients with head and neck cancer (HNC), incorporation of AHPs in the entire healthcare process is particularly important. HNCs are heterogeneous both biologically as well as in clinical behaviour, and grow relatively fast in an anatomically and functionally complex area<sup>13,14</sup>. Patients often have problems with speech, swallowing, and physical disfigurement due to treatment<sup>15,16</sup>, requiring the collaboration of both medical specialists (MSs) and AHPs. Therefore, high-quality integrated care for patients with this type of tumour is needed<sup>17,18</sup>.

We aimed to develop a set of QIs through an evidence-based method to measure the quality of oncological integrated care. This study can serve as an example for quality dashboards for other oncological diseases to monitor and improve the integrated care.

## MATERIALS AND METHODS

### Study design

We used the RAND-modified Delphi method (RMDM) to develop indicators of integrated care from the perspective of MSs and AHPs using four steps. The Committee on Research Involving Human Subjects in the Arnhem–Nijmegen region of the Netherlands assessed the study and concluded that our study was carried out in accordance with the applicable rules concerning the review of research ethics committees and informed consent.

### Setting

In the Netherlands, where approximately 3000 patients are newly diagnosed with HNC each year. HNC care is centralized in eight university hospitals and six affiliated centres (14 hospitals)<sup>19</sup>. MSs and AHPs involved in HNC care are united in two national foundations, one for MSs (NWHHT) and one for AHPs (PWHHT). In addition, there are two patient organisations: 'Klankbord' and 'NSVG'

(now merged into '*Patiëntenvereniging Hoofd-Hals*'). The first represents all patients with HNC, the latter represents laryngectomized patients.

### **Expert panels and patients**

Members of both national foundations were asked to deliver experts with a key role in HNC care, to select a set of QI. The panel of MSs ( $n = 18$ ), with one or two representatives from each hospital consisted of six otorhinolaryngologists, six oral and maxillofacial head and neck surgeons, three radiation oncologists, and two medical oncologists; an epidemiologist from the Netherlands Cancer Registry was added. The panel of AHPs ( $n = 11$ ) included all board members of the national foundation. The board represents all kinds of AHPs related to the HNC in the Netherlands. The panel of AHPs consisted therefore of one physiotherapist, two speech therapists, three dieticians, two oral hygienists, two oncology nurses, and one radiotherapy technician.

Each hospital and the two Dutch patient organisations were asked to select one or two HNC patients willing to participate in the patient panel. The two chairmen of both patient organisations were invited to participate. In total, 12 patients and the two chairmen participated (mean age of 60 years; 57% male; either a tumour in the larynx (46%) or oral cavity (54%)).

### **Step 1: Selection of key recommendations**

A comprehensive literature search was carried out on guideline recommendations, existing indicators regarding outcome, process, and structure of integrated HNC care, and possible case-mix factors. CINAHL, MEDLINE, PubMed, and the Internet were searched for literature and national and international guidelines regarding the perspective of both the MSs and AHPs. The following search terms were used: quality assessment, practice guidelines, and quality indicator in combination with the different types of head and neck cancer. For a clear overview, recommendations and indicators found in the literature regarding the process and structure of care delivered by MSs were assigned to one of four topics, particularly diagnostics, treatment, aftercare and follow-up, and coordination and organization. Those of allied healthcare were assigned into one of six topics, particularly nutritional care, dental care, psychosocial care, physical care, communication and information, and coordination and organization. In addition, potential outcome indicators found in the literature, were added to this overview. Subsequently, all recommendations from the guidelines, and existing indicators from the literature were processed in a questionnaire for individual rating by panel members. To assess which case-mix factors could be important to assess possible variation between the hospitals, we performed another literature search and also added a list of case-mix factors to the questionnaire, asking both panels to verify them.

## Step 2: Individual rating of key recommendations by the expert panels

Both panels received an online and paper version of the questionnaire, starting with similar outcome indicators and case-mix factors, followed by recommendations and indicators regarding the process and structure of either MS care or AHP care, including the origin. Both panels were instructed to rate the recommendations and indicators on a nine-point scale (1 = lowest rating, 9 = highest rating) with regard to relevance on four criteria: (1) prolonging disease-free and overall survival; (2) improving quality of life; (3) quality of the healthcare process; and (4) improving efficiency. The MS panel was instructed to rate the outcome indicators first, and AHPs were then asked if they agreed with the selected outcome indicators, and if other outcome indicators should be added. Members were invited to discuss their ratings with professionals in their own hospital, and encouraged to propose new indicators and give feedback on proposed case-mix factors.

The results of Step 2 were summarized in a feedback report to facilitate Step 3. The cutoff for a high median was set at 8 or higher<sup>20,21</sup>. Panel members were defined as being in agreement if at least 70% of the ratings fell in the same tertile (e.g. 1–3, 4–6, or 7–9). If less than 70% of the scores fell in the same tertile, this was an indication of no agreement. Disagreement was defined when at least 30% of the scores were in both the bottom (1–3) and top (7–9) tertiles<sup>22</sup>. Three different categories were assigned following the individual rating and the level of agreement: (1) selection, (2) discussion, and (3) no selection.

## Step 3: The panel consensus meetings

Personalized summary reports provided panel members of both panels with the opportunity to compare their individual scores with overall distribution and means. Discussions resulted in three different scenarios for the recommendations and indicators in, respectively, categories 1–3: (1) include; (2) reformulate or omit; and (3) omit. Suggestions on the proposed case-mix factors and added recommendations and indicators were also discussed.

## Step 4: Approval of the final set

Selected recommendations regarding the process of care were formulated into indicators by determining the numerator (total number of patients who received the care that was being measured or that met the experience) and the denominator (total number of patients who needed to receive the care or to experience the outcome). For selected recommendations regarding the structure, the percentages of characteristics that were present in the care setting were determined.

The concept version of the set of QIs from MSs and AHPs was sent to both panels by email for final remarks and for approval. In addition, the patient panel members were asked to give



their feedback and to approve the concept version during a personal meeting. Feedback from all three panels was incorporated and the final set was produced.

## **RESULTS**

### **Step 1: Selection of key recommendations**

The selection procedure resulted in 42 and 45 recommendations and indicators from the MS<sup>6,23-33</sup> and AHP perspective, respectively<sup>11,12,25-27,31,34-39</sup>.

### **Steps 2 and 3: Individual rating and panel consensus meetings**

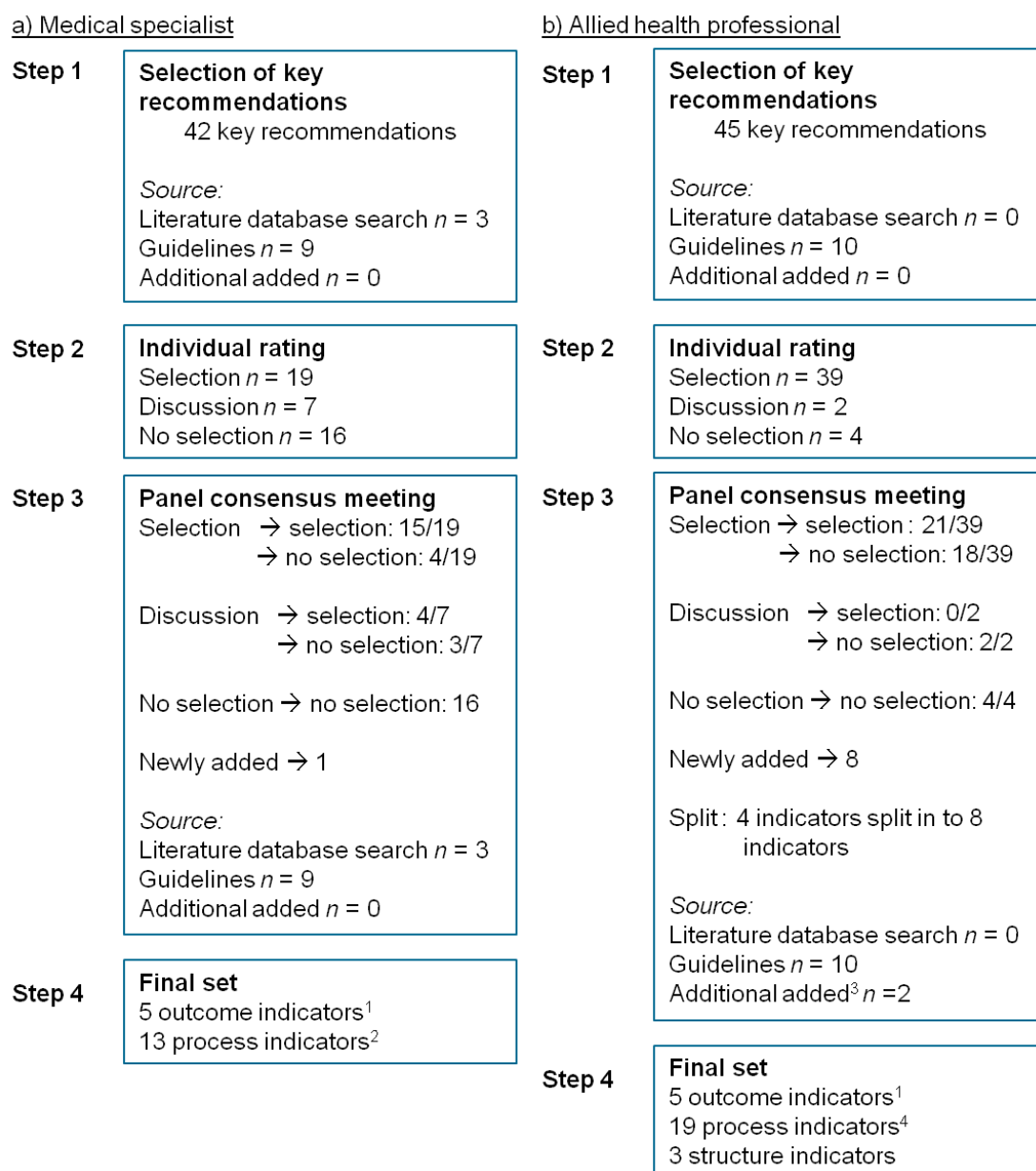
There was a 100% response rate of both panels to the questionnaires. All outcome indicators ( $n = 5$ ) were selected by the MSs and approved by the AHPs.

#### ***Medical specialists***

A total of 19 out of 26 recommendations and indicators in the categories 'selection' and 'discussion' were accepted (Figure 1). All panel members agreed that all 16 recommendations and indicators in the category 'no selection' should be omitted. Five new items (Step 2) were added during the consensus meeting: one recommended that each patient discussed in the MTM should have been seen in a HNOC before treatment. The other four were complications from treatment that were added to the outcome indicator concerning complications. One recommendation regarding the integrated record-keeping was defined as a structure indicator.

#### ***Allied health professionals***

A total of 21 out of 39 recommendations and indicators in the category 'selection' were accepted (Figure 1). All recommendations and indicators in the categories 'discussion' ( $n = 2$ ) and 'no selection' ( $n = 4$ ) were omitted. Four selected recommendations were split into eight recommendations. In all, eight new recommendations were added by the panel concerning the possibility of referral to centres for special dental care, the availability of AHPs during treatment, the possibility of movement research by physiotherapists, and the availability of structured follow-up treatment or structured transfer by physiotherapists. Five recommendations were defined as structure indicators. These concerned accessibility of psychological scores, presence of the case manager or nurse practitioner, presence of the AHPs at the MTM, availability of the AHPs at the MTM, and assignment of a nurse to every 100 new patients.



**Figure 1.** Selection of indicators for both medical specialists (MSs) (a) and allied health professionals (AHPs) (b).  
<sup>1</sup>Outcome indicators were selected by the MSs and approved by the AHPs. <sup>2</sup>After exclusion of two indicators in the second approval round, namely: the structure indicator about integrated record keeping and the newly added indicator (patient should have been seen in the Head and Neck Oncology Center). <sup>3</sup>Two additional guidelines were added by the panel. <sup>4</sup>After exclusion of six indicators (two structure indicators: presence of the AHPs at the multidisciplinary team meeting (MTM) and availability of the AHPs at the MTM, and four process indicators: measuring mouth opening, referral when mouth opening is smaller than 3.5 mm, measuring shoulder function by physiotherapist, assessment of patient by oral hygienist), two indicators were merged together (information about effects of alcohol and smoking), and one indicator was added (scattering caps for prevention of mucositis) in the second approval round.

### Step 4: Approval of the final set

After approval in the first round by the panel, a second round was organized with a selection of panel members to minimize the set. This resulted in a final set of five outcome indicators, 10

case-mix factors, 13 and 19 process indicators from the MS and AHP perspective, respectively, and three structure indicators from the AHP perspective (Tables 1-4, Figure 1). Both concept versions of the MSs and AHPs were approved by all three panels.

## Content of the final set in integrated care

Outcome indicators formed the basis of the process and structure indicators, and both panels agreed on the following integrated care outcome indicators: healthcare status (for example 'no evidence of disease'), tumour recurrence, complications (regarding surgery, radiotherapy, and chemotherapy), quality of life, and patient experiences (Table 1). Case-mix factors were assigned to characteristics of the patient, tumour characteristics, and treatment characteristics (Table 2).

In order to measure the quality of integrated care for patients with HNC, the first part of the indicator set focused on the diagnostic phase, with attention to the pathological report, the treatment plan, the MTM, presence of the case manager at the MTM and at the conversation informing the patient of their prognosis. The second part of the indicator set focused on the treatment phase, with special attention to the involvement of the physiotherapist, the dental team (including oral hygienist), dietitian, speech therapist, and psychologist. The third part of the indicator set focused on the aftercare, control of the thyroid function, and involvement of the speech therapist and physiotherapist during follow-up. In particular, the relevance of an MTM and involvement of different AHPs before and after treatment were also mentioned as being crucial by the patient panel.

Indicators defined as being important for the overall integrated care process were: visualization of waiting times during the care process, informing patients about the effects of smoking and alcohol, and assuring a structured medical transfer. In particular, waiting times were defined as a relevant aspect of healthcare by the patient panel. Three indicators were relevant at the hospital level rather than at the patient level.

**Table 1.** Outcome indicators from the perspective of both the medical specialists and the allied health professionals and agreed by patients.

Outcome indicators
<b>Healthcare status of the patient</b> (NED = no evidence of disease; AWD = alive with disease; DOD = dead of disease; DID = dead of intercurrent disease (disease at the same time); DTC = dead of treatment complications)
<b>Tumour recurrence</b>
<b>Complications</b> (regarding surgery, radiotherapy, and chemotherapy)
<b>Quality of life</b>
<b>Patient experience</b> (experience with healthcare providers, information and communication, shared decision-making, coordination of care, guidance and support, completion of treatment, and follow-up)

**Table 2.** Case-mix factors from the perspective of both the medical specialists and the allied health professionals and agreed by patients.

Case-mix
<b>Unchangeable characteristics of the patient</b>
- Age
- Sex
- Education level
- Ethnicity
<b>Changeable characteristics of the patient</b>
- Living situation
- Intoxications (smoking/alcohol)
- Co-morbidity
- Performance status at intake
<b>Tumour characteristics</b>
- Diagnosis (i.e. TNM, site, ICD-O, and type of tumour)
<b>Treatment characteristics</b>
- Details of surgery, radiotherapy and chemoradiotherapy

**Table 3.** Final set of process indicators from the perspective of the medical specialists and agreed by allied health professionals and patients.

Process indicators medical specialists
<b>Diagnostics</b>
<b>Pathology report</b>
- Pathological status of the tumour
<b>Multidisciplinary team meeting (MTM)</b>
- Presence of practitioner who is responsible for the patient in the MTM
- MTM takes place before treatment of the patient
- Presence of other disciplines in the MTM
<b>Treatment plan</b>
- Treatment plan available
- Conditions for treatment plan
<b>Treatment</b>
<b>Dental team</b>
- Involvement of dental team when treated with radiotherapy
<b>After care</b>
<b>Physiotherapist</b>
- Involvement of physiotherapist when treatment consists of neck dissection
<b>Thyroid function</b>
- Control of thyroid function
<b>Coordination and organization</b>
<b>Waiting time</b>
- Referral to the hospital
- Finishing diagnostics
- Start first treatment
- Start second treatment (when applicable)

**Table 4.** Final set of process and structure indicators from the perspective of the allied health professionals and agreed by medical specialists and patients.

Process indicators allied health professional
<b>Dietitian</b>
- Malnutrition screening
- Malnutrition monitoring
- Referral to dietitian
<b>Psychologist</b>
- Psychological screening
- Psychological screening results registered in patient record
- Relevance of referral discussed with patient
<b>Oral hygienists</b>
- Fluoride caps for prevention of caries due to radiotherapy
- Use of salt/soda solution by the patient
- Scattering caps for prevention of mucositis
<b>Physiotherapist</b>
- Control of movement
- Referral to physiotherapist by the physician
- Structured medical transfer or follow-up treatment when at high risk of shoulder disability
<b>Speech therapist</b>
- Rehabilitation of swallowing, speech, and/or voice complaints
- Use of swallow screening, fiberoptic endoscopic evaluation of swallowing, and/or video fluoroscopy
- Follow-up on swallowing, speech, and/or voice complaints
<b>Communication and information</b>
- Information about effects of alcohol and smoking
<b>Coordination and organization</b>
- Presence of case manager/nurse practitioner at conversation to discuss prognosis
- Structured medical transfer to external allied health professionals and general practitioner
- Presence of case manager/nurse practitioner at the MTM
<b>Structure indicators</b>
- Accessibility of psychological screening scores in patient record
- Presence of case manager/oncology nurse for 4 days a week
- Assignment of a nurse to every 100 new HNC patients

## DISCUSSION

This is one of the first studies to select a minimum set of QIs covering the entire healthcare process of patients with HNC in integrated care with a systematic procedure. QIs were based on national and international guidelines and the literature, including the MS and AHP perspectives, and were approved by a patient panel. The set consisted of outcome, process, and structure indicators, and case-mix factors. A total of five outcome indicators and 10 case-mix factors from both perspectives, 13 and 19 process indicators from the MS and AHP perspective, respectively, and three structure indicators from the AHP perspective were developed.

The final set of indicators focused on the care aspects during the diagnostic, treatment, and follow-up phases. This set highlighted that, in each phase, integrating the care provided by both the MSs and AHPs is essential to guarantee high-quality care. Both panels independently proposed similar indicators regarding the involvement of the physiotherapist and the dental team. However, the indicators from the MSs were more focused on the diagnostic phase and organizational aspects, such as waiting times, whereas the indicators from the AHPs were more focused on the functional and psychosocial status of the patient before, during, and after treatment<sup>1,18,27,28</sup>. A total of four indicators were directed towards waiting times. From the perspective of patient centeredness, it is crucial to reduce waiting times; this was also emphasized in our patient panel. In addition, some research shows that waiting time is negatively related to survival<sup>40</sup>. A total of five indicators were directed towards the MTM. Also in our patient panel, the MTM was discussed in detail and seen as an important aspect of care. This underlines the relevance of a MTM for high-quality care and is in line with current research indicating that the use of a MTM results in better clinical and process outcomes<sup>41,42</sup>.

Previous research towards quality indicators focused on only one type of HNC or a single part of the healthcare process; for example, the multidisciplinary team, physician performance<sup>6,7,23</sup>. Ouwens et al.'s research on the quality of integrated care for patients with HNC, mainly focused on process indicators. In our study, a set was established in which the outcome indicators were the most important, forming the basis of our process and structure indicators<sup>24</sup>.

### Strengths and weaknesses

First, this set of indicators was based on integrated multidisciplinary HNC care. Porter showed that it is relevant to measure the value over the full care cycle rather than one department<sup>43</sup>. Second, outcome indicators formed the basis of the process and structure indicators, and were approved by the patient panel. Porter stated that value in healthcare should be defined by the consumer and measured by the outcomes achieved and less by process of care<sup>43</sup>. Lastly, the method used in this study, RAND-modified Delphi method, incorporates expert opinions, which reduces the risk of the unintentional influence of stakeholders on the results of the development

process<sup>5</sup>. However, the indicator set is still extensive. The expectation is that testing the set in practice for validity, reliability, and feasibility will reduce the number of significant QIs.

As a next step, a pilot will be performed in the 14 hospitals to test the indicators empirically on feasibility and clinimetrics. The developed QIs of integrated care for patients with HNC can be used to build a quality dashboard for other oncological diseases that also need integrated care.

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## CHAPTER 3

# Needs and preferences of patients with head and neck cancer in integrated care



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Clinical Otolaryngology. 2017; [Epub ahead of print]

## **ABSTRACT**

**Objectives:** Incorporation of patients' perspectives in daily practice is necessary to adapt care to users' needs. However, information on patients' needs and preferences for integrated care is lacking. The aim was to explore these needs and preferences, taking patients with head and neck cancer (HNC) as example, to adapt current integrated care to be more patient-centred.

**Design:** Semi-structured interviews were held with current and former patients and chairmen of patient associations. Relevant needs and preferences were identified and categorized using the eight-dimension Picker model of patient-centred care.

**Setting:** Integrated HNC care hospitals in the Netherlands.

**Participants:** Patients with HNC and chairmen of two Dutch HNC-patient associations.

**Main outcome measures:** Patients' needs and preferences of integrated HNC care categorized according the Picker model.

**Results:** A total of 34 themes of needs and preferences were identified, by 14 patients with HNC or their delegates, using the Picker dimensions. Themes often emerged were as follows: personalization of healthcare regarding patients' values; clear insight into the healthcare process at organizational level; use of personalized communication; education and information that meets patients requirements; adequate involvement of allied health professionals for physical support; more attention to the impact of HNC and its treatment; adequate involvement of family and friends; adequate general practitioner involvement in the after care; and waiting time reduction.

**Conclusions:** Monitoring the identified themes in integrated HNC care, fitting in the Picker model, will enable us to respond better to the needs and preferences of patients, and patient-centred care in oncological care can be enhanced.

## INTRODUCTION

Head and Neck Cancer (HNC) is the sixth most common cause of cancer worldwide<sup>1</sup>. HNC and its treatment has significantly impact on a patient's well-being as HNCs grow relatively quickly in an anatomically and functionally complex area<sup>2,3</sup>. Patients often experience problems with speech, swallowing, and physical disfigurement due to treatment<sup>4-7</sup>. In addition, they often suffer from psychological disorders, such as depression and anxiety, and social problems, such as relationship difficulties with their partner and family members, and loss of work<sup>8-10</sup>. Therefore, HNC care is complex, requiring medical specialists and allied health professionals to collaborate throughout the entire healthcare process from the diagnostic phase until the surveillance phase. A strategy for better coordination of services across the entire care continuum with optimal alignment and collaboration of all disciplines is required<sup>11</sup>.

Nowadays, providing patient-centred care is an essential component of high quality integrated care<sup>12</sup>. Responding to the needs and preferences of patients for the delivery of healthcare is an important aspect of current healthcare policy worldwide<sup>13,14</sup>. It leads to positive clinical outcomes, for example better survival<sup>13</sup> or physical and emotional recovery<sup>15</sup>, and increased patient satisfaction<sup>16</sup>. Increased patient satisfaction might result in a better adherence to treatment recommendations and increase quality of life<sup>17</sup>.

Patient-centred care has been defined as "care which is responsive to consumer needs, values and preferences; integrated and coordinated; relieves physical discomfort; provides emotional support; allows for the involvement of family and friends; and supports the provision of information, communication and education to enable patients to understand and make informed decisions about their care"<sup>12</sup>. Also, this definition points out that patient-centred care is relevant during the entire healthcare process. However, until now, information on patients' needs and preferences for integrated cancer HNC care is lacking.

We aimed to identify all possible needs and preferences of Dutch patients with HNC in integrated care to obtain tools to make current integrated HNC care more patient-centred. By identifying those themes of healthcare where improvement regarding patient-centeredness is necessary, optimizing integrated care for patients with HNC is possible.

## MATERIALS AND METHODS

### Study design

In this exploratory study, semi-structured interviews were held until data saturation (the point at which no new information was mentioned in interviews<sup>18</sup>) was reached with current and former patients and the chairmen of two HNC patient associations. The aim of the interviews was to identify all possible needs and preferences of patients with HNC, to discuss these explored needs and preferences in a group meeting with all participants and to check whether new items came

forward. The Medical Ethical Committee (CMO) of the region Arnhem–Nijmegen assessed the study and declared that ethical approval was not necessary. The study is in agreement with the COREQ checklist.

## Setting

In the Netherlands, where approximately 3000 patients are yearly diagnosed with HNC, HNC care is centralized in 14 hospitals: eight Head and Neck Oncology Centres (HNOCs) and six affiliated centres<sup>19</sup>. The affiliated centres have committed themselves to using the same treatment protocols as the related HNOCs. There are two Dutch patient associations: ‘*Stichting Klankbord*’ and ‘*NSVG*’. Currently, they collaborate in one Dutch patient association ‘*Patiëntenvereniging Hoofd-hals*’.

## Participants

Research shows that 13–15 interviewees are usually sufficient to reach data saturation<sup>18</sup>. Therefore, each of the 14 hospitals and both Dutch patient associations were asked to select one or two patients using the following inclusion criteria: the patient was diagnosed with HNC, was treated with a curative or palliative intention, and had the capacity to overview his own healthcare process. In addition, the two chairmen of both patient associations were asked to participate (Table 1).

**Table 1.** Characteristics of participating patients.

	Age, years	Sex (n)	Type of tumour (n)	Type of treatment	Year of diagnosis
Patient 1	67	Male	Larynx	Operation & radiotherapy	2009
Patient 2	52	Male	Larynx	Operation & radiotherapy	2008
Patient 3	56	Female	Larynx	Operation & chemoradiation	2004
Patient 4	59	Male	Oral cavity	Operation	2013
Patient 5	60	Male	Oral cavity	Operation & radiotherapy	2011
Patient 6	66	Female	Larynx	Operation & radiotherapy	2004
Patient 7	58	Female	Oral cavity	Operation	2011
Patient 8	67	Female	Larynx	Operation & radiotherapy	2009
Patient 9	56	Female	Larynx	Operation & radiotherapy	2011
Patient 10	58	Male	Oral cavity	Chemoradiation	2012
Patient 11	65	Male	Oral cavity	Operation & radiotherapy	2005
Patient 12	50	Female	Oral cavity	Operation & radiotherapy	2009
Chairman 1	58	Male	Larynx	Operation & radiotherapy	1997
Chairman 2	69	Male	x	x	x

Participants were approached either by telephone or email, depending on their ability to talk clearly on the phone. This was followed up by a letter or email to confirm their participation and a request to sign an informed consent form. A total of 12 patients and the two chairmen participated in the semi-structured interviews either by telephone ( $n = 8$ ) or in person ( $n = 6$ ). One of the two chairmen is a former patient with HNC. Only one chairman of a patient organisation was part of the steering committee of a project where the study was part of. There was no relationship with the other interviewees.

## Data collection

An expert panel developed a structured interview guide (Appendix 1). The interview guide contained open-ended questions and optional questions to deepen each topic. The interview guide contained four sections, referring to the referral, the diagnostic, treatment, and follow-up phases of HNC care. In each section, similar questions were asked emphasising the received healthcare in the specific phase. Questions focused on the needs and preferences, involvement of and communication among the different healthcare providers, strong and weak points of the received healthcare, and points for current healthcare improvement. The interview (lasting 30–45 minutes) conducted by the first author (female, MSc Biomedical sciences, PhD student, experience for interviewing obtained in her master) was fixed regarding the sections, each interview started with the referral and ended with the follow-up phase. Within a section, the questions were flexible depending on the answers of the interviewee. The pilot for the interview was done with the first and the last author (female, senior researcher, experience with qualitative research). Patients did not receive questions in advance and were not informed about the use of the framework to analyze the data using the eight-dimensions Picker model.

## Analysis

A deductive approach was used with the eight-dimensions Picker model as a basis for our analyzes (Table 2). This model contains dimensions regarding patient-centeredness of care and served as a theoretical framework for the analyzes of the interviews<sup>20,21</sup>. The model embodies the conviction that all patients deserve high-quality patient-centred care. The eight dimensions appear important and relevant in several European countries and in the USA<sup>22,23</sup>. Expressed needs and preferences were categorized into Picker dimensions using the following four steps; step 1: marking expressed needs and preferences with codes; step 2: categorizing codes dealing with the same subject into similar items; step 3: categorizing items dealing with the same topic into similar themes; and step 4: categorizing themes into the Picker dimensions. For step 1, interviews were recorded using an audio recording device, transcribed verbatim and qualitatively analyzed using ATLAS.ti (version 7). To enhance the reliability and validity, coding was done by two researchers: the first and third author (female, BSc Medicine, inexperienced). The first four interviews were coded open ended independently by both researchers<sup>24</sup>. Hereafter, codes were

compared and discussed until consensus was reached. One concept coding tree was made, e.g. axial coding, that was used to provide some support for the remaining interviews and to stimulate the researchers to keep the same focus<sup>24</sup>. In addition, both researchers could add, remove or move codes of the coding tree. Codes of the last ten independently coded interviews were compared and discussed until consensus was reached. Hereafter, the coding tree was finalized and the following steps were taken. Steps 2-4 were carried out by the same two researchers. Disagreement was discussed between the two researchers and if needed classified with the last author (female, PhD) until consensus was reached. We aimed to fit all themes into the Picker dimensions, new dimensions were proposed if codes would not fit.

**Table 2.** Definition of the eight Picker dimensions translated to the Dutch situation.

<b>Picker dimensions</b>	<b>Definition of each dimension</b>
1. Respect for patient-centered values	An awareness of quality-of-life issues, involvement in decision-making, dignity, and attention to patient's needs and autonomy
2. Coordination and integration of care	Care across clinical, ancillary, and support services and in the context of receiving front-line care
3. Information, communication, and education	On clinical status, progress, prognosis, and processes of care to facilitate autonomy, self-care, and health promotion by healthcare providers or patients themselves
4. Physical comfort	Pain management, help with activities of daily living, and clean and comfortable surroundings
5. Emotional support and alleviation of fear and anxiety	Support with issues such as clinical status, prognosis, and the impact of illness on patients, their families, and their finances
6. Involvement of family and friends	Involving family and friends in decision-making and awareness and accommodation of their needs as caregivers
7. Transition and continuity of care	Information that will help patients care for themselves away from a clinical setting, and coordination, planning, and support to ease transitions
8. Access to care	Attention to time spent waiting for admission, diagnostics, treatment(s) or time between appointments in the hospital and with allied health professionals

## RESULTS

All invited patients and chairmen participated in the study (Table 1). A total of 34 themes of needs and preferences were analyzed (Table 3 and Figure 1), and all were categorized into the Picker dimensions. All needs and preferences were discussed and approved in a group meeting with all participants. For a comprehensive and clear overview of the results, beneath we give a summary of most often mentioned themes in each domain with an explanation.

## **Respect for patient-centred values**

The most important two themes that the interviewees mentioned regarding patient-centred values, were the expectation for personalized care regarding their individual values and assertiveness. Personalized care was expressed by the interviewees as listening to the patient, taking the patient seriously and incorporating the patient's wishes into the healthcare process. To deliver personalized healthcare, interviewees mention that it is important that patients are assertive. For more assertive patients, it is easier to express their issues and questions, resulting in better care adapted to the needs of the patient.

## **Coordination and integration of care**

An important aspect mentioned in this domain was the relevance of the healthcare process at the organizational level being clear. It was pointed out that this would increase the confidence of the patient in the healthcare provided, which might reduce their feeling of being ill.

In addition, involvement of allied health professionals, including oncology nurses, and peers at the right time in the healthcare process, according to the patient's needs, was also noted as being valuable. For example, the first patient does not prefer the involvement of a dietician, a second patient prefers the involvement of a dietician right after the diagnosis to give all available information about nutrition specified for the health process, and a third patient prefers the involvement of a dietician just before start of the treatment to give the most important information that is relevant at that time point, and the rest of the information can follow on a later time point.

## **Information, communication, and education**

Important themes mentioned by the interviewees were the requirements for communication, information and education, and training of healthcare providers. Requirements mentioned by the interviewees were clear, honest, complete and repeated information and communication. This can increase trust in the healthcare provided and reduce possible feelings of uncertainty and doubt. Interviewees also pointed out that healthcare providers should be trained very well. This includes sufficient knowledge about HNC, the ability to communicate, as well as the skills and attitudes of healthcare professional.

## **Physical comfort**

Interviewees mentioned that the involvement of the physiotherapist and speech therapist should be in line with patients' preferences, as well as the amount of support during the aftercare that should be provided. In addition, interviewees mentioned the restrictions and disadvantages of devices. More high-quality devices will increase the motivation of patients to sport and go out again.



**Table 3.** Expressed needs and preferences categorized into the Picker dimensions.

Domains	Themes	Corresponding items
1. Respect for patient-centered values	Personalized care regarding patient values	Healthcare providers should listen to the patient, take the patient seriously, and incorporate the patient's wishes into the treatment plan. In addition, they should give the patient the feeling that there is enough time and attention for the patient.
	Assertiveness relevant in personal healthcare	Assertiveness of the patient is relevant to deliver personalized healthcare. Patients can come with their own questions towards healthcare professionals and can indicate better what they prefer. The amount of assertiveness required depends on the attitude of the healthcare professional.
	Emotional support towards inability to speak	It is important to support the patient who has lost the ability to speak. For patients it is very frightening and frustrating to realize and to experience the loss of voice.
	Hospital facilities	A clinic with a warm atmosphere results in calmness. In addition, a hospital room adapted to patients wishes is preferred.
	Doctor–patient relationship	Integrity and mutual respect are necessary for a good doctor–patient relation.
	Disease physically demanding as a single person	More attention should be given to single persons in order to cope with the physical barriers, especially in the first phase of recovery.
2. Coordination and integration of care	Clarity about healthcare process	The healthcare path should be clear regarding what the patient can expect, this means that each step that will be taken in the diagnostic phase will be clear. This is also expected of the treatment (especially regarding the operation).
	Personalized involvement of allied health professionals	Involve allied healthcare professionals before or after the treatment, depending on patients' preferences and the advice of the healthcare professional. However, there should always be an option to meet the allied healthcare professional.
	Availability of a contact person	Patients need to have one known person available in the multidisciplinary integrated healthcare team who can answer questions and address health-related issues. The contact person should be often available.
	Involvement of oncology nurse and peers as personal experts	It is important to involve peers as personal experts, and they are valuable for the patient on multiple timepoints. In addition, involving oncology nurses might result in time saving during the consult with the doctor, and also it is described as a more personal contact.
	Personalized involvement of peers	Involve peers before or after the treatment, depending on patients' preferences and the advice of the healthcare professional. Nevertheless, the healthcare professional should always offer the option to meet a peer.
	Personalized diagnostic phase	Adjust the number of diagnostic appointments one after the other according to patients' preferences and combine medical consultations.
	Home care for both patient and partner	Besides support for the patient, home care should be directed towards the partner as well.

Domains	Themes	Corresponding items
3. Information, communication, and education	Communication, information, and education meets requirements	Communication, information and education should be clear, honest, complete, and be repeated. It is acceptable to tell uncertainties about the healthcare process, as long as the information is clear. Information on the internet should be of good quality.
	Training of health professionals	Healthcare providers should have enough knowledge about HNC, the ability to communicate properly, and good skills and attitudes of doctors and nurses. In addition, a good preparation before the appointment and thoroughness of the healthcare provider is expected.
	Personalized communication, information, and education	A patient should receive information and education in line with patients' preferences on how and when it is given and which information is most valuable. Information from peers additionally is preferred. However, too many information for a patient is difficult to understand.
	Stimulation of perseverance of patients	It is important that healthcare providers stimulate the patient in order to motivate the patient during recovery.
	Patients want to contribute to improvement in healthcare	Patients do not mind to contribute to improvement in healthcare, for example by giving information and education to healthcare professionals.
	Training of professionals in the home care	Home care should be provided by a specialized qualified healthcare provider, someone who knows the impact and effects of surgery and someone who knows how to act in an efficient, non harmful and quick way.
	Transparent healthcare	It should be clear to the patients which hospitals deliver good quality of healthcare.
4. Physical comfort	Personalized involvement of allied health professionals for physical support	Involvement of physiotherapy or speech therapy should be in line with patients' preferences, also the amount of support during the aftercare that should be provided.
	Solutions for limitations of devices	Solutions for the restrictions and disadvantages of devices, which emerge especially during physical exercise, will increase the motivation of patients to sport.
5. Emotional support and alleviation of fear and anxiety	Personalized psychological support for emotional problems	It is important to offer psychological care to every patient, and then to deliver the care as desired by the patient. In addition, some allied health professionals, like a physiotherapist or speech therapist, sometimes tend to function in such a way that they can deliver emotional support as well.
	Attention to the impact of HNC and its treatment	More attention should be given to the major impact of HNC and its treatment on patients' life, and also it is important to keep in mind the differences that men and women cope with the disease differently.
	Personalized involvement of peers for emotional support	Important to involve peers as personal experts, especially for emotional support.
	Emotional support of GP in aftercare	The GP should be very assertive to give emotional support to the patient during after care, at the time that care provided by the hospital will be less.

Domains	Themes	Corresponding items
6. Involvement of family and friends	Good carer makes allied health professionals and peers less relevant	Support from family and friends is important for psychosocial support, rehabilitation, and reintegration. In addition, involvement of family and friends during the diagnosis and treatment is a major support. A caregiver at home makes allied health professionals and peers less needed.
	Personalized involvement of family	There should be the option to involve family and friends, for example the option to bring relatives to hospital appointments and the extent to which children are involved in the healthcare process.
7. Transition and continuity	Good transfer from health professionals in the hospital to health professionals in the home situation	The hospital plays an important role in ensuring good transfer from the hospital to the home situation of the patient.
	Involvement of GP in aftercare for optimal transfer	The GP should be included in the healthcare transfer to ensure better support once the patient has returned home.
	Cooperation of allied health professionals and hospital for optimal transfer	There should be a good cooperation between healthcare professionals in the hospital and in the home care situation.
8. Access to care	Delay due to GP, dentist, general hospital, and the patient themselves	Delays in the first phase, before diagnosis, are often caused by the general practitioner, the dentist or the general hospital. In addition, patients themselves can also cause the delay since they postpone the first visit.
	Short waiting times in hospital and before operation	Short waiting times for an appointment and for a operation are preferred, it will decrease the psychological burden that might occur during the waiting.
	Waiting time necessary for recovery between two treatments	Waiting time between two treatments might result in a better recovery; physical and psychological.

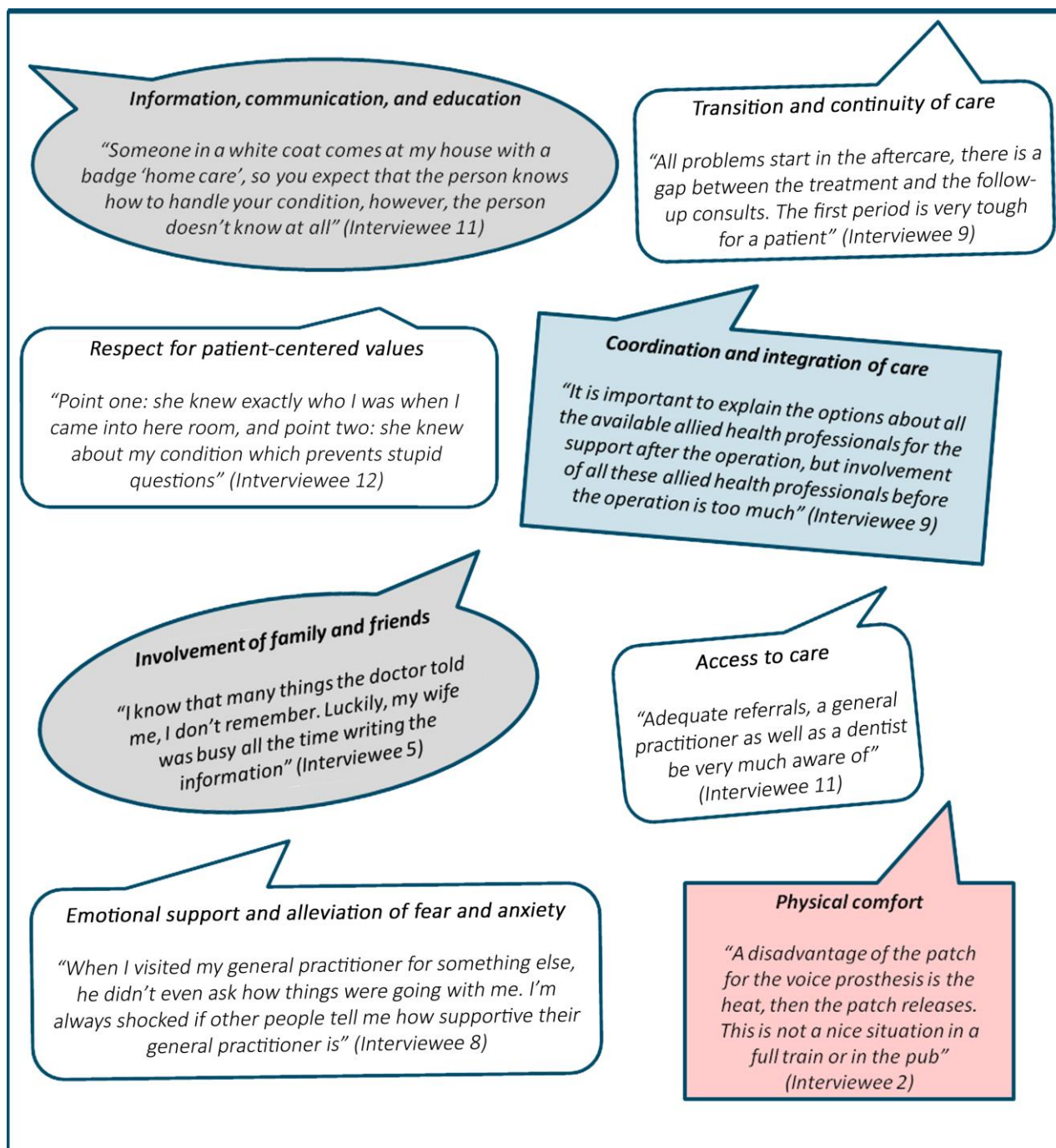
\* GP = general practitioner

## Emotional support and alleviation of fear and anxiety

An important aspect of care mentioned by the interviewees was the involvement of psychological support at patient's preference, given by a psychologist but also by any allied health professional. In addition, interviewees mentioned that more attention should be given to the major impact of HNC and its treatment. Furthermore, emotional support from the general practitioner (GP) during aftercare was mentioned as being highly important as the support from the healthcare providers from the hospital will decrease. Less or no involvement might result in fear and feeling of helplessness of the patient.

## Involvement of family and friends

Support from family and friends was mentioned as highly important. Even, they concluded that a good partner or carer makes the allied health professionals less relevant in this situation. Furthermore, interviewees mentioned the involvement of family as an important issue. Particularly regarding children: how do you involve children?



**Figure 1.** Quotations expressed by current and former HNC-patients and the chairmen of two HNC-patient associations for each Picker dimension.

### Transition and continuity of care

An aspect that often emerged, according to the interviewees, was the 'gap' between the hospital and the home situation. The interviewees considered it important to better organize the transfer to reduce this void. To better organize the transfer, it is important to include the GP in the

healthcare transfer; particularly, the GP should be well informed about the medical condition of the patient to prevent that a patient needs to inform the GP him/herself. In addition, the cooperation of the allied health professionals and the hospital is crucial. This includes knowledge of each other's discipline and reduction of repetition of care processes, which can increase trust in healthcare and might ensure optimal recovery.

### **Access to care**

The most important aspect in this domain concerned the delay between the visit to the GP or the dentist and the first appointment at a specialized hospital. This was caused either by the GP, dentist, or the general hospital, or by the patients themselves. Therefore, it is important to increase the knowledge about HNC to decrease the first delay. Secondly, they noted that there is an urgent need to reduce waiting times in the hospital, particularly prior to the start of treatment. On the other hand, they indicated that the waiting time between two treatments might result in a better recovery.

## **DISCUSSION**

This study identifies a total of 34 themes of patients' needs and preferences, categorized according to the eight-dimension Picker model regarding patient-centeredness of care, for current integrated HNC care. The main themes emerging from the interviews were the personalized care regarding patient values (Respect for patient-centred values), a clear healthcare process at an organizational level (Coordination and integration of care), personalized communication and information that meets requirements (Information, communication, and education), involvement of allied health professionals for physical support (Physical comfort), more attention to the impact of HNC and its treatment (Emotional support), adequate support from family and friends making support from allied health professionals less necessary (Involvement of family and friends), adequate involvement of the GP in the after care (Transition and continuity), and reduction of waiting times prior to the start of the treatment (Access to care).

Unique for this study is that it demonstrates needs and preferences of HNC-patients over the entire healthcare process from the diagnostic phase until the surveillance phase. In addition, it demonstrates the relevance of both patient-centred care and integrated care for patients with HNC; two important aspects of healthcare published previously<sup>12,15,25</sup>. After analyzes of the interviews, we identified many themes that fitted easily into the Picker dimensions of patient-centred care, for example, the need for personalized communication, and the need for more attention to the impact of HNC and identified conditions to optimize transfer from the hospital to the home situation. In addition, needs and preferences for healthcare delivered by both medical

specialists and allied health professionals emerged in the interviews. For example, the expertise and professionalism of doctors and the doctor-patient relationship are needs and preferences that refer to the medical specialist. Personalized involvement of allied health professionals for physical and emotional problems is an example of needs and preferences that refer to the allied health professional. However, personal preferences of the patient should not interfere with the best possible healthcare as described in evidenced-based guidelines. The task of a(n allied) health professional is to deliver evidence-based practice by incorporating best available evidence, clinicians' judgement and patient values and preferences. Herewith, the healthcare can be both personal based and evidence-based<sup>26</sup>.

### **Suggestions for daily practice**

Patients in our study expect an active involvement of GPs at referral, during transfer, and for emotional support in the aftercare. GPs' engagement can be increased by involving them in the multidisciplinary team meetings before determining the treatment<sup>27</sup> and before discharge of the patient<sup>28</sup>. In the last case, a patient-specific follow-up plan can be developed together with the GP, the specialist and the patient. Other initiatives exist to give the right support to GP's to develop their own role and to provide the best care for patients with cancer. Examples of these initiatives are the Macmillan Cancer support in the UK or Oncological Networks in the Netherlands<sup>29</sup>. Moreover, multimedia campaigns such as The Make Sense campaign can increase the awareness and knowledge of patients, health professionals (including GPs) and society regarding head and neck cancer symptoms and subsequently drive earlier presentation, diagnosis and referral<sup>30</sup>. Therefore, it is important that more people know that this campaign exists.

### **Strengths and weaknesses**

The selection of patients from across the spectrum of Dutch hospitals, and the inclusion of representatives from the patient associations are strengths of this study. The aim of this explorative study was to identify all possible needs and preferences of patients with HNC and not to give a representative set of their needs and preferences. Therefore, only data saturation was needed, which we indeed reached with our 14 patients<sup>18</sup>. A disadvantage might be that we only included patients, diagnosed with an oral cavity carcinoma or laryngeal carcinoma. However, most cancer treatments, independent of the type of HNC cancer, follow similar healthcare processes. Therefore, we think that most expressed needs and preferences for HNC care are relevant for both the included and not included HNC cancer types. In addition, the included two tumour types represent 55% of the patient population in the Netherlands.

## Conclusions

Patients' needs and preferences for integrated oncological care were identified to obtain tools to make current care more patient-centred. Knowing the patients needs and preferences helps to improve healthcare accordingly. The next step is to quantify the expressed needs and preferences among a representative population, to explore to what extent the needs and preferences are met in practice and which has the highest priority.

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## Appendix 1 - Interview guide

### General information

Name:

Age:

Diagnosis:

Year of diagnosis:

Type of treatment:

### A. Received healthcare

For each contact moment (A1 to A7) we focused on the following questions:

- What involved this process? How did it look like?
- How was the experience with the process? What went well, what could have been better? Why?
- Were allied health professionals involved in the process? Was the involvement of allied health professionals as you preferred? If yes, why? If not, why?
- What would be any improvement for the process?

A1. before referral to specialized hospital? (GP and/or peripheral hospital)

A2. at first appointment in the specialized hospital?

A3. during diagnosis?

A4. at the consultation where the treatment plan was discussed?

A5. during preparation of the treatment?

A6. during treatment?

A7. during the follow-up phase?

### B. Specific organizational aspects in the received healthcare

For each organizational aspect (B1 to B3) we focused, beside specific questions/topics, on the following questions:

- How did you experience the process?
- Was it as expected?
- What could have been better?

B1. Communication

- Was there one contact person? Did you prefer that?

- Was communication clear about appointments, parking, with health professionals?

B2. Information

- Did you understand everything?

- Was the information enough?

- Was information given in the right format?

- Was family involved if you preferred?

- Were peers involved if you preferred?

- Was information repeated?

B3. Organization and coordination

- Clear where you were expected?
- Waiting times
- Enough time for you as a patient

B4. Transfer to GP

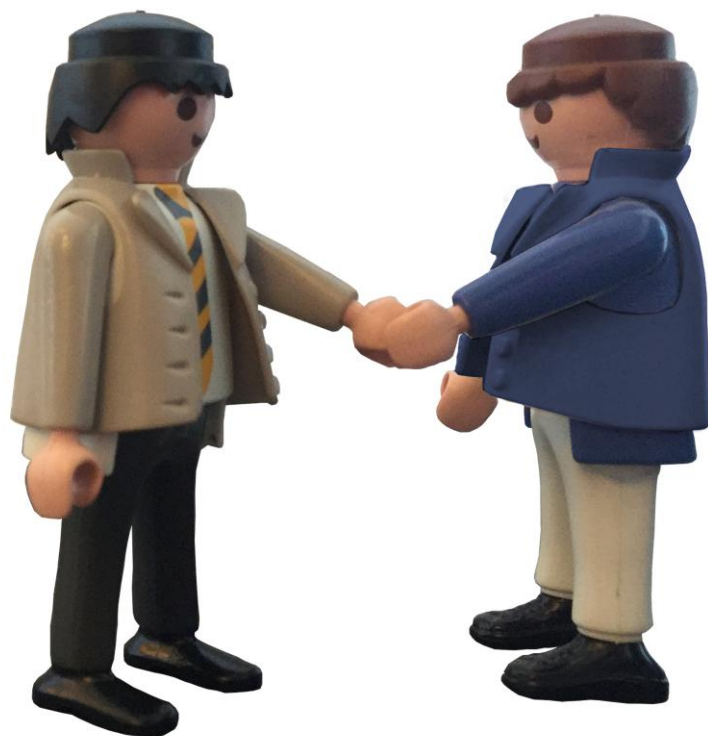
**C. Overall experience**

- What was your best experience?
- What was your worst experience? And what improvement would you suggest?
- What would you suggest for future healthcare?



## CHAPTER 4

### **Variation in integrated head and neck cancer care: impact of patient and hospital characteristics**



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Submitted

## ABSTRACT

**Objectives:** Monitoring and effectively improving oncologic integrated care requires dashboard information based on quality registrations. The dashboard must include evidence-based quality indicators (QIs) that measure the quality of integrated multidisciplinary care. We aimed to assess the quality of current integrated head and neck cancer care with QIs, the variation between Dutch hospitals, and the influence of patient and hospital characteristics.

**Methods:** Previously, 39 QIs were developed from the perspectives of medical specialists, allied health professionals, and patients. Data for calculating QI scores were collected by self-registration of 1667 curatively treated patients in eight hospitals. Only QIs with a patient sample larger than 400 were included so that we could calculate reliable QI scores. We used multilevel analysis to explain the variation.

**Results:** Current care varied from 29% for the QI about a case manager being present to discuss the treatment plan to 100% for the QI about the availability of a treatment plan. Variation between hospitals was small for the QI about the percentage of patients discussed in multidisciplinary team meetings (adherence: 95%, range 88–98%) and large for the QI about malnutrition screening (adherence: 50%, range 2–100%). At the patient level, higher QI scores were associated with lower performance status, an advanced tumour stage, and tumour in the oral cavity and oropharynx. At the hospital level, higher QI scores were associated with more curatively treated patients (volume).

**Conclusion:** Although the quality registration was only recently launched, it already visualises hospital variation in current care. Four determinants were influential: tumour stage, performance status, tumour site, and volume. However, more data are needed to assure stable results for use in quality improvement.

## INTRODUCTION

The WHO stated in 2006 that even when healthcare systems are well developed and resourced, quality remains a serious concern<sup>1</sup>. Therefore, it is important to gain insight into the care that is actually provided in order to monitor and effectively improve high-quality care<sup>2,3</sup>. The management of high-quality integrated care, with optimal alignment and collaboration of all the disciplines involved throughout the healthcare process, is complex<sup>4-6</sup>. Hence, measuring and monitoring the quality of integrated care is crucial. This can be done by using a dashboard of valid and reliable quality indicators (QIs)<sup>7,8</sup>. A QI is defined as "a measurable element of practice performance for which there is evidence or consensus that it can be used to assess the quality of care"<sup>3</sup>. Many QIs have already been developed for oncologic diseases<sup>9,10</sup> and non-oncologic diseases<sup>11</sup>.

Head and neck cancer (HNC) is the sixth most common cause of cancer worldwide<sup>12</sup>. HNC and its treatment have a significant impact on a patient's well-being because HNCs grow relatively quickly in an anatomically and functionally complex location<sup>13-16</sup>. Patients often experience problems with speech, swallowing, and physical disfigurement due to surgery, systemic therapy, radiation, or a combination of such treatments<sup>17-21</sup>. It is crucial to an optimal result that medical specialists and allied health professionals deliver integrated care throughout the care process.

In 2014, a dashboard in the form of a quality registration, with evidence-based QIs, was developed for measuring the quality of integrated care for patients with HNC in eight Dutch head and neck oncology centres (HNOCs) and six affiliated centres, e.g. the Dutch Head and Neck Audit (DHNA)<sup>22</sup>. The goal of this quality registration was to give HNOCs more insight into their current care delivery, to compare themselves to other HNOCs, and to improve HNC care. However, the start-up of a quality registration takes several years before stable data can be obtained<sup>23</sup>.

Besides stable data, data at patient and hospital levels that might influence the quality of care are needed for calculating QIs in assessing current care and the variation in care between different HNOCs and affiliated centres. Insight into determinants that influence variation in care at patient and hospital levels can provide tools for explaining the QI scores and improving current care by medical staff learning from each other<sup>24</sup>.

We aimed to obtain insight into the quality of currently delivered HNC care in the Netherlands and some of the influencing characteristics. This is the first paper with results, in which we assessed the quality of current integrated HNC care on the basis of QI scores from a recently launched quality registration that collects data prospectively: the DHNA. We have determined the hospital variation in QI scores and explored this variation to see whether differences at patient and hospital levels explain it. We used both the current care evaluation and the determinants of variation in care to test the value of the QI set as an instrument for monitoring and improving clinical performance for this quality registration<sup>25</sup>.

## **METHODS**

### **Study design**

This is a prospective observational multicentre study for measuring current quality of integrated HNC care with a recently launched quality registration including 39 evidence-based QIs<sup>22</sup>. Hospital variation and determinants at patient and hospital levels were assessed.

### **Setting**

In the Netherlands, where approximately 3000 HNC patients are diagnosed annually, HNC care is centralised in 14 hospitals: 8 head and neck oncology centres (HNOCs) and 6 affiliated centres<sup>26</sup>. The affiliated centres have committed themselves to use the same treatment protocols as the related HNOCs. The number of patients treated annually varies between 70 and 600 per centre. The various medical specialists and allied healthcare professionals involved in HNC care are united in two national foundations, one for medical specialists and one for allied health professionals. There is also one Dutch HNC patient association. Together, they developed evidence based QIs to initiate a quality registration: the Dutch Head and Neck Audit (DHNA).

### **Study population**

All patients with HNC newly diagnosed in the period December 2013 to January 2017 that were treated with a curative intention in one of the 14 HNOCs and affiliated centres were eligible for registration in the DHNA.

### **Quality indicator set**

All 39 QIs had been systematically developed and based on national and international evidence-based guidelines. For this purpose, the two national foundations for medical specialists and allied health professionals, and the patient association, used the Rand modified Delphi method<sup>22</sup>. This resulted in five outcome indicators, 13 and 18 process indicators from the perspective of medical specialists and allied health professionals, respectively, and three structure indicators from the perspective of the allied health professionals. In addition, a total of 10 determinants at patient level were selected: age, gender, smoking, alcohol, marital status, nationality, performance status, tumour site, clinical TNM, and comorbidity<sup>13,22,27-29</sup>. The only determinant at hospital level was volume, e.g. the average number of patients curatively treated annually in the HNOCs and affiliated centres<sup>30,31</sup>. This was based on the number of curatively treated patients per year in the HNOCs and affiliated centres as registered by the Netherlands Comprehensive Cancer Organisation<sup>32</sup>.

## Data collection

Health professionals working in the participating hospitals used an online self-registration system to collect the necessary data for calculating QI scores and assessing determinants at patient and hospital levels. The outcome indicators focused on survival, recurrence, complication rate, and patient-reported outcomes and experiences. The process indicators focused on performance in the diagnostic, treatment, and follow-up phases, as well as aspects regarding coordination and communication. The structure indicators focused on the numbers of available case managers and nurses for each hospital. We subdivided the determinants into the following categories: age (continuous); gender (male versus female); smoking (never smoker versus former smoker and current smoker); alcohol (never drinker versus former drinker and current drinker); WHO performance status (0 versus 1–4); tumour site ([oral cavity and oropharynx] and [larynx and hypopharynx] versus [other]); tumour, nodes, and clinical TNM stage (early [I–II] versus advanced [III–IV]); and comorbidity (yes versus no) at patient level, and the volume of HNOCs and affiliated centres (<200 patients versus >200 patients) at hospital level.

## Sample size

Previous research shows that the precision of a QI score depends on the number of patients included (numerator)<sup>33</sup>. For individual QIs, a sample of about 400 patients is required for calculating a precise indicator score with a confidence limit of plus or minus 5 percentage points. Therefore, only QIs with a numerator of more than 400 patients were included.

## Data analyses

The inclusion criteria for the analysis were: 1) the patients had to be curatively treated, 2) there had to be enough data for each patient (at least the age and date of the start of the first treatment), and 3) there had to be at least 30 patients per hospital<sup>34</sup>. The last inclusion criterion assured that results were not skewed unfairly because of too few data.

## Descriptive analyses

For each indicator we assessed:

- 1) The numerator: the total number of patients who received the care as recommended in the QI
- 2) Indicator score: the quotient of the number of patients who received care as recommended in the QI compared to the number of patients who received the care as recommended
- 3) Missing data: the percentage of missing values per indicator. Missing data for indicators may bias the results. A percentage exceeding 25% refers to poor data quality<sup>35</sup>.



## Determinant analyses

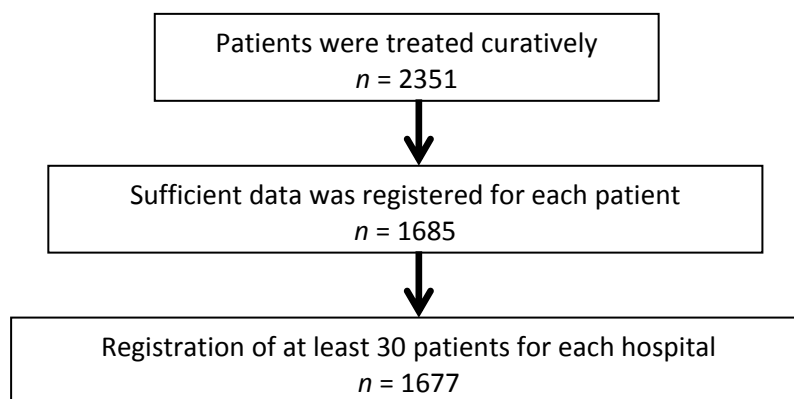
To assess determinants at patient and hospital levels, we first studied the single relationship between indicators (e.g. percentage of patients discussed in a multidisciplinary team meeting (MTM) before start of the treatment) and determinants that could influence the indicator score (e.g. tumour site).

We tested determinants that had an association with indicator scores ( $p < 0.20$ ) together in a multilevel logistic regression model to account for the nested structure of data from individual patients (level 1) nested within hospitals (level 2). We automatically excluded patients (list-wise deletion) from the analysis if indicator or determinant data were missing and the missingness was ignorable. Missingness was defined as the state in which data were randomly missing as was seen by comparing the population included for each indicator with the original population of the study. We needed a minimum of 10 patients for each degree of freedom in the model to develop a reliable multilevel model. Odds ratios with 95% confidence intervals described the association between indicator scores and determinants. To assess to what extent these determinants explained suboptimal adherence (<90%) we recalculated the indicator scores by stratification. If multiple determinants were associated with a single indicator, we combined the different determinants and calculated stratified scores for the different categories.

## RESULTS

### Study population

In total, 1667 patients satisfied the inclusion criteria for this analysis. The patients originated from five HNOs and three affiliated centres (Table 1 and Figure 1). The median age of the patients was 65 years (range 64–68 years) and most were male (69%; range 60–72%). Missing data for most patient characteristics varied between 0% and 32%. However, 75% of the data for comorbidity were missing. Regarding volume, three out of eight HNOs and affiliated centres were classified as low-volume centres (<200 curatively treated patients) (Table 2).



**Figure 1.** Inclusion of patients in this study. Sufficient data = at least the age and date of the start of the first treatment are known.

**Table 1.** Characteristics of 1667 patients from eight hospitals based on the inclusion criteria

	Results		Missing data (%)*
	n	Range	
<b>Median age at start of treatment (y)</b>	1667	65 years (64–68years)	0.0
<b>Gender</b>			0.1
Male	1142	68.5% (60–72%)	
Female	524	31.5% (29–40%)	
<b>Tobacco smoking</b>			28.7
Never smoker	220	18.9% (15–34%)	
Former smoker	462	39.7% (18–43%)	
Current smoker	483	41.5% (33–65%)	
<b>Alcohol use</b>			27.5
Never drinker	272	23.4% (11–41%)	
Former drinker	88	7.6% (5–18%)	
Current drinker	801	69.0% (41–76%)	
<b>Performance status</b>			32.0
No performance status	80	8.5% (1–97%)	
Performance status registered	862	91.5% (3–100%)	
<b>Score</b>			0.8
Score 0 (perfect health)	570	66.7% (10–92%)	
Score > 0	285	33.3% (8–90%)	
<b>Tumour site</b>			0.1
Oral cavity and oropharynx	666	47.7% (43–61%)	
Larynx and hypopharynx	437	31.3% (15–42%)	
Other	293	21.0% (16–32%)	
<b>Clinical TNM stage</b>			21.1
Early (Stage ≤ 2)	582	47.1% (39–59%)	
Advanced (Stage >2 )	654	52.9% (39–66%)	
<b>Comorbidity</b>			75.0
Yes	415	0%	
No	0		

\*Low percentages registered in the category 'unknown' are not presented.

**Table 2.** Number of patients diagnosed in the period December 2013 to January 2017 of which data was registered in the audit for each hospital.

Hospital	No. of patients
Hospital 1	47
Hospital 2	111
Hospital 3	252
Hospital 4	480
Hospital 5	234
Hospital 6	55
Hospital 7	64
Hospital 8	424

## Current HNC care and variation

A total of nine process indicators had a numerator above 400 patients: 7 from the medical specialists perspective and 2 from allied health perspective (Table 3). The indicator for a case manager or nurse practitioner being present at the consultation to discuss the treatment plan had the lowest score and a high variation (adherence to QI9 was 29%; range 0–90%), and the indicator for the availability of a treatment plan had the highest score (adherence to QI2: 100%; no range). The scores of three process indicators for a MTM and treatment plan had an adherence larger than 90%, and the variation between hospitals was small: particularly a MTM before treatment of the patient (QI1): 95%, range 88–98%, availability of a treatment plan (QI2): 100%, no range, and registration of whether the patient was treated according to protocols (QI3): 97%, range 86–99%. The scores of three indicators of lead time varied between 48% and 83% adherence, with the lowest score for starting the first treatment within 30 calendar days from the first consultation (QI7: 48%, range 24–78%) and the highest score for finishing diagnostics within 21 calendar days (QI6: 83%, range 63–100%). The variation between hospitals was the largest for malnutrition screening (QI8: 50%, range 2–100%). Three indicators had more than 25% of missing data, particularly for involvement of a dental team before radiotherapy, start of the first treatment within 30 days, and malnutrition screening.

## Determinants

Comorbidity, nationality, and marital status had 75% or more missing data and were therefore excluded from further analysis. Multilevel analyses showed that three determinants at patient level and one determinant at hospital level influenced the scores of six indicators significantly, namely: tumour stage, tumour site, performance status, and volume (Table 4). Patients with an advanced tumour stage or tumour in the oral cavity or oropharynx compared to larynx and hypopharynx were associated with larger adherence to indicator scores for involvement of the dental team (QI4) (exclusion of T1 larynx carcinoma), finishing diagnostics within 21 calendar days (QI6), malnutrition screening (QI8), and a case manager or nurse practitioner being present at the consultation to discuss the treatment plan (QI9). Imperfect health (high performance score) is associated with low indicator scores for malnutrition screening. High volume centres were associated with better adherence to indicator scores for registration whether the patient has been treated according to the protocol (QI3), for referral to the hospital within 7 calendar days (QI5), and for finishing diagnostics within 21 calendar days (QI6). Stratified QI scores varied from the original QI scores (Tables 3 and 4). The lowest increase of adherence, from 28.9% to 30.4%, was seen for the QI about the presence of a case manager or nurse practitioner at the consultation to discuss the treatment plan. The greatest increase of adherence, from 49.9% to 81.9%, was seen for the QI for malnutrition screening.

**Table 3.** Results of indicators from medical and allied health professional perspectives.

No.	Topic – Indicators (perspective)	Numerator (n)	Indicator score (%)	Range between hospitals (%)	Missing data (%)	Influencing patient characteristics
1	Multidisciplinary team meeting takes place before treatment of the patient (MS)	877	95.4	88–98	14.1 <sup>A</sup>	X
2	Treatment plan available (if patient discussed in MTM before start of the treatment) (MS)	836	100	0	18.1 <sup>B</sup>	NA
3	Registration if patient is treated according protocol (MS)	835	97.2	86–99	17.7	Volume
4	Involvement of dental team before start of radiotherapy (MS)	713	83.7	67–100	25.1 <sup>C</sup>	Tumour stage
5	Referral to the hospital (within 7 calendar days) (MS)	975	79.6	53–100	4.5	Volume
6	Finishing diagnostics (within 21 calendar days) (MS)	1010	82.6	63–100	1.1	Tumour site & Volume
7	Start first treatment (within 30 calendar days) from first consult (MS)	978	48.4	24–78	26.3	X
8	Malnutrition screening at intake or before start of treatment (AHP)	619	49.9	2–100	39.4 <sup>A</sup>	Tumour stage & Performance status
9	Presence of case manager/nurse practitioner at consultation to discuss the treatment plan (AHP)	1013	28.9	0–90	0.8 <sup>A</sup>	Tumour site

AHP = allied health professional, MS = medical specialist

<sup>A</sup>Patients for whom at least the intention of the treatment is clear and for whom diagnostics are carried out

<sup>B</sup>Patients for whom at least the intention of the treatment is clear, diagnostics are carried out, and there is a treatment plan

<sup>C</sup>Patients for whom at least the intention of the treatment is clear, and they are treated with radiotherapy

**Table 4.** Patient and hospital characteristics that influence scores of indicators in multilevel analyses and the corresponding stratified indicator score.

No.	Topic – Indicators	Patient characteristic	n	OR [95% CI]	Indicator score (%)
3	Registered whether patient is treated according to protocol	Volume	138 674	Low volume: REF High volume: 2.255 (1.073–4.740)	Low volume: 93.2 High volume: 99
4	Involvement of dental team before start of radiotherapy	Tumour stage	204 411	Early: REF Advanced: 3.066 (1.901–4.946)	Early: 72.5 Advanced: 90.3
5	Referral to the hospital (within 7 calendar days)	Volume	1096 67	Low volume: REF High volume: 3.521 (1.722–7.196)	Low volume: 57.1 High volume: 85.1
6	Finishing diagnostics (MTM; within 21 calendar days)	Tumour site	220 485 304	Other: REF *(1) 1.710 (1.102–2.652) (2) 0.889 (0.564–1.399)	Other & low volume: 55.8 (1) & low volume: 70.3 (2) & low volume: 62.3
		Volume	135 699	Low volume: REF High volume: 3.692 (1.342–10.162)	Other & high volume: 86.4 (1) & high volume: 90.6 (2) & high volume: 82.1
8	Malnutrition screening at intake or before start of treatment	Tumour stage	220 309	Early: REF Advanced: 4.110 (2.466–6.849)	Early & PS = 0: 56.6 Early & PS >0: 23.6
		Performance status	270 199	PS = 0: REF PS >0: 0.595 (0.356–0.995)	Advanced & PS = 0: 81.9 Advanced & PS >0: 38.1
9	Presence of case manager or nurse practitioner at consultation to discuss the treatment plan	Tumour site*	204 426 280	Other: REF (1) 0.627 (0.403–0.974) (2) 0.487 (0.303–0.781)	Other: 37.7 (1) 30.8 (2) 30.4

\*(1) = Oral cavity and oropharynx , (2) = Larynx and hypopharynx  
MTM = multidisciplinary team meeting, PS = Performance status

## DISCUSSION AND CONCLUSION

We aimed to assess the variation of current head and neck cancer (HNC) care between Dutch hospitals and the influence of patient and hospital characteristics. The quality of current care was low for the QI on the presence of a case manager at the consultation to discuss the treatment: the case manager was present in nearly one-third of all hospitals. There was hardly any variation between hospitals for the QI about the percentage of patients discussed in the MTM. However, almost all hospitals scored differently, with a variation from 2% to 100%, for the malnutrition screening QI. Four characteristics at patient and hospital levels had a large influence on indicator scores: tumour stage, performance status, tumour site, and volume of HNC patients.

Previous research shows that care, despite national guidelines, is not always delivered in the same way in different hospitals<sup>36,37</sup>. We also found a large variation between care delivery from the perspectives of medical specialists and allied health professionals. The largest variation was for QIs from the perspective of allied health professionals – perhaps because there are hardly any evidence-based guidelines. Regarding patient characteristics, there was a small increase in the stratified QI scores for the single determinants tumour stage and tumour site compared to the raw QI scores. However, if the QIs were calculated for both different tumour stages and performance status, the stratified QI score was much larger than the raw QI score. Both determinants are often used for case mix correction and prognosis of survival<sup>38</sup>. If indicators are to be used to compare the quality of care between hospitals, adjustment of the indicator scores might be needed. When more data is available in the future, the prognostic value of patient characteristics for survival could be investigated. Regarding hospital characteristics, previous studies show an association between varying hospital volume and survival<sup>30,39</sup>. We determined the influence of hospital volumes on our QI set and found a positive influence of hospital volume on lead time and registration if a patient is treated according to the protocols. In the future, the association between volume and patient outcomes, such as survival and recurrence percentage, can also be assessed for patients with HNC to investigate whether further concentration of HNC care in the Netherlands is beneficial.

Other countries already have databases with the aim of improving quality of care and patient outcomes; for example, the Head and Neck Audit (HANA) in the UK and the Danish head and neck cancer database<sup>40,41</sup>. A difference with our database is that the Dutch Head and Neck Audit (DHNA) relies on evidence-based QIs from the three different perspectives of medical specialists, allied health professionals, and patients. The other databases are mostly set up from an epidemiological perspective and form a base for clinical trials. An epidemiologic database is not primarily intended for quality registration. Apart from our initiative with quality of care data, De Ridder et al. have published a retrospective cohort evaluation study about the variation in HNC care in the Netherlands<sup>36</sup>. They show hospital variation in volume and treatment of especially oropharyngeal and oral cavity cancer. However, conclusions were drawn from retrospective data that were collected for a purpose other than quality registration. The set-up

and prospective character makes the DHNA far more suitable for measuring and monitoring the quality of HNC care.

Low indicator scores do not necessarily mean that the quality of care is poor, it is rather a signal to evaluate further. Possible explanations could be that care is not given according to the guidelines, the guideline does not fit daily practice, or the quality of the data is poor. Dentler et al. define good-quality data as being available, complete, and correct. Further, they show that data quality can influence indicator results<sup>42</sup>. Our quality registration is in the start-up phase. The availability of our data does not seem optimal: a total of four out of eight determinants and three out of nine indicators had more than 25% of missing data, which is too much. Regarding completeness, it is crucial to include all the existing patients before we can say anything about general healthcare<sup>43</sup>. At this moment, the registration is not complete, and centres with low inclusion must be encouraged to include more patients. Regarding correctness, data from the DHNA will be compared with data from the Netherlands Cancer Registry (NCR), which is managed by the Netherlands Comprehensive Cancer Organization (IKNL). However, in the past years, the online self-registration system has improved due to the optimising of registration guidelines and the learning curve of health professionals. Therefore, in the future we expect better data quality.

## **Strengths and limitations**

A strong point of this study is that it makes it possible to assess evidence-based QI scores for nearly 1700 patients. Because only indicators with a numerator of more than 400 patients were taken into account for calculating a precise indicator score, insight into the total quality of care for patients with HNC was impossible. In addition, data quality criteria such as availability, completeness, and correctness need further improvement. We will achieve this by giving feedback about missing data and indicator scores, advising on improvement processes, and validating the registered data. Furthermore, more data is necessary to perform a reliable case-mix correction. On the basis of the opinions of the caregivers involved in the registration, collection of data seems to be difficult and time consuming. Focus on less labour-intensive registration systems and more automatic data collection is needed, particularly registration at the source. Initiatives in the United States and the Netherlands have already started<sup>44,45</sup>.

## **Conclusion**

Initiating a multidisciplinary quality registration based on evidence-based QI is challenging. Main requirements are guidelines to develop QIs, and sufficient data to evaluate the QI, to determine case-mix, and to assess the effects of variation on outcomes. However, our recently launched audit visualises already the variation in current care among hospitals that deliver HNC care. One of the following steps for the DHNA will be more research to explore the association of variation in quality of care with differences in patient outcomes and identifying targets for quality improvement.

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## CHAPTER 5

# Patient-reported outcomes and experiences in Dutch integrated head and neck cancer care



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Submitted

## **ABSTRACT**

**Objectives:** Monitoring how patients feel and what they experience during the integrated care process gives health professionals tools to improve their care. To obtain more information about specific improvements for different treatment methods, we aimed to measure patient-reported outcomes (PROs) and patient-reported experiences (PREs) in integrated care for patients with head and neck cancer receiving monomodality or multimodality treatment.

**Methods:** We recruited patients from three hospitals participating in the Dutch Head and Neck Audit. Validated PRO measures (PROMs) were completed at baseline and 3, 6, and 12 months after the last treatment. The PRE measures (PREMs) were completed at 12 months after diagnosis. Descriptive analyses were used to assess trends in PROs over time, differences between monomodality and multimodality treatments in PROs and PREs, and differences in patient characteristics in PROs and PREs.

**Results:** A total of 345 patients completed 571 PROMs, and 71 patients completed PREMs. In general, patients with multimodality treatments tend to have poorer functional scores and more symptoms than patients with monomodality treatment. In addition, patients receiving radiotherapy treatment alone have poorer functional scores and more symptoms than patients with surgery alone. Regarding PREs, patients receiving multimodality treatment reported slightly more frequently poorer experiences than patients receiving monomodality treatment.

**Conclusions:** Given the greater incidence of symptoms and loss of functioning among patients after multimodality treatment, the follow-up phase should be more personalised and directed toward rehabilitation for restoring function and decreasing symptoms.

## INTRODUCTION

Integrated care is defined as 'the methods and type of organization that will provide the most cost-effective preventative and caring services to those with the greatest health needs and that will ensure continuity of care and co-ordination between different services'<sup>1</sup>. Management of high-quality integrated care is particularly complex due to the optimal alignment and collaboration of all the disciplines involved throughout the entire healthcare process<sup>2-5</sup>. Hence, measuring and monitoring the quality of integrated care is crucial; for example, by using a dashboard of valid and reliable quality indicators (QIs)<sup>5,6</sup>. Many QIs have already been developed for both oncologic diseases<sup>7-9</sup> and non-oncologic diseases<sup>10</sup>.

In recent years, more attention has been paid to the use of outcome indicators in quality measuring and monitoring, as well as to process and structure indicators. This is particularly true for patient-reported outcomes (PROs) and patient-reported experiences (PREs) measured with patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs). These outcomes provide information about the patients' feelings and experiences during the healthcare process. This information can be used as feedback to the hospital and healthcare provider as a starting point for healthcare improvement<sup>11</sup>. Such outcomes also give patients the opportunity of monitoring their own health during treatment and follow-up; and they give health professionals the opportunity to personalise the healthcare process<sup>12,13</sup>. Therefore, outcomes and experiences from patients' perspectives are increasingly used to measure quality of care and, if necessary, to improve it. Greenhalgh and colleagues report that only occasionally health professionals do use PROs during treatment and follow-up to improve the quality of care<sup>14</sup>. However, Basch and colleagues state in a recent publication that integration of PROs into routine care for patients with metastatic cancer was associated with increased survival compared to usual care. They indicate that early responsiveness to patients symptoms prevents further adverse effects<sup>13</sup>.

A prime example of the need of high-quality oncologic integrated care is the delivery of care to patients with head and neck cancer (HNC). HNC and its treatment have a significant impact on the patient's well-being because HNCs grow relatively quickly in an anatomically and functionally complex area<sup>15-17</sup>. Patients often experience problems with speech, swallowing, and physical disfigurement due to treatment<sup>18-20</sup>. The treatment may consist of surgery, radiation therapy, systemic therapy (monomodality treatment) or a combination of treatments (multimodality treatment). Optimal alignment and collaboration of both medical specialists and allied health professionals is crucial for an optimal result. In 2014, evidence-based QIs were developed to measure the quality of integrated care for patients with HNC at eight Dutch head and neck oncology centres (HNOCs) and six affiliated centres, i.e. the Dutch Head and Neck Audit (DHNA)<sup>21</sup>. The goal of this quality registration was to enable HNOCs to obtain insight into their current care delivery, to compare themselves to other HNOCs, and to improve HNC care. The PROs and PREs were included as outcome indicators in the DHNA. Since data at patient level

might influence the indicators, they were included as possible case-mix factors<sup>15,22</sup>. However, the questions remain whether there will be differences in outcomes and experiences between different types of treatments and different subgroups of patients, and how we can use the PROs and PREs to improve healthcare.

For this purpose, we measured PROs and PREs in integrated HNC care to assess how patients feel and how they experience integrated care. We determined the differences between monomodality treatment and multimodality treatment to obtain information about specific aspects of different treatment methods to be used for improving care. In addition, we assessed specific trends in both PROs and PREs of patients with differences in gender, age, and tumour stage to determine whether rehabilitation varies among different subgroups.

## **MATERIALS AND METHODS**

### **Study design**

In a prospective, observational, multicentre study, patients receiving integrated HNC care measured PROs and PREs so that researchers could assess trends in PROs over time, differences between monomodality treatment and multimodality treatment in PROs and PREs, and differences between different patient characteristics in PROs and PREs.

### **Setting**

Approximately 3000 HNC patients are diagnosed in the Netherlands annually<sup>23</sup>. HNC care is centralised in 14 hospitals: eight HNOCs and six affiliated centres. The affiliated centres have committed themselves to use the same treatment protocols as the related HNOCs. The various medical specialists and allied healthcare professionals involved in HNC care are united in two national foundations, one for medical specialists and one for allied health professionals. There is also one Dutch patient association for head and neck cancer. The Dutch Federation of University Medical Centres (NFU) and health insurer CZ jointly initiated the set-up of a quality registration that uses evidence-based QIs: the DHNA. The PROs and PREs are included as the main outcome indicators in the DHNA, along with survival, recurrence rates, and complication rates.

### **Study population**

All patients included in the DHNA were asked to fill in the questionnaires. The DHNA inclusion criteria for HNC patients were: a diagnosis of a primary HNC tumour and curative treatment for it in one of the 14 Dutch participating hospitals in the period November 2014 to February 2017.

## Questionnaires

### *PROMs*

Two different validated PROMs were included in the DHNA. The European Organization for Research and Treatment of Cancer Quality-of-Life Questionnaire (EORTC QLQ-C30) comprises 30 questions grouped in six function scales (Global health status, Physical, Role, Emotional, Cognitive, and Social functioning) and nine symptom scales (examples are Insomnia and Fatigue). This questionnaire complements the EORTC Head and Neck Cancer Module (H&N35), which consists of 35 questions grouped in 18 symptom scales (examples are Pain, Sticky saliva, and Problems with social eating)<sup>24-26</sup>. A higher score on the function scales means better functioning. A higher score on the symptom scales means more problems for the patient. Both questionnaires have been exclusively tested in several populations, as well as in several languages and cultural settings<sup>24</sup>. The questionnaires were digitally completed at baseline and 3, 6, and 12 months of follow-up after the last treatment. 'Baseline' was defined as the date of diagnosis during multidisciplinary team meetings.

### *PREMs*

The consumer quality index for oncologic care (CQO) is a PREM designed to measure the performance of healthcare providers and patients' experiences in healthcare<sup>27</sup>. The CQO is based on the international Consumer Assessment of Healthcare Providers and Systems (CAHPS). It has been validated in several settings and originally contained eight domains. The CQO included in the DHNA was expanded with needs and preferences expressed by patients in a previous study<sup>28</sup>. In total, one domain and 15 separate questions were added. The questionnaire was digitally completed at 12 months after diagnosis.

## Data collection

An oncology nurse asked the patients if they were willing to complete PROMs and PREMs. Health professionals working in the hospitals that are included in the DHNA used an online self-registration system to collect the necessary data for calculating QI scores and patient characteristics. In addition, PROMs and PREMs were sent automatically at pre-defined moments by a specific application in the self-registration system. In this system, all patients gave informed consent by clicking the button stating 'I agree' before completing the questionnaires. All data for PROMs, PREMs, indicators, and patient characteristics were collected in a pseudonimised database. The relevant patient characteristics for this study were age, gender, and tumour stage.

## Data analyses

All the domains of the PROMs were included in the analyses. Since we were specifically interested in aspects of integrated care, we analysed the following domains of the PREMs:



Organisation, Attitude of health professionals, Expertise of health professionals, Information & Communication, Patients' own contributions, Continuity & Coordination, and Guidance & Support. All variables from the PROMs were transformed to scales from 0 to 100 and divided into scale scores according to the EORTC QLQ-C30 rules and the H&N35 Scoring Manual<sup>29</sup>. Specific patterns of the various follow-up moments were analysed. In addition, we assessed whether these patterns differed in monomodality treatment and multimodality treatment. Monomodality treatments were split into surgery alone and radiotherapy alone since quality-of-life aspects differ depending on which treatment the patient received. Clinical relevance was set at a difference of 10 or more points on a scale of 0 to 100 in the EORTC symptom scores<sup>18,30</sup>. We descriptively analysed the PREM results with calculated domain scores according to the scoring manual in three different categories: Never/Sometimes, Mostly, and Always. We determined whether every participant had completed at least 50% of the questions for each domain. Participants who had not were excluded from the analysis for the domain in question. In addition, we analysed these patterns to see if they differed in monomodality treatment and in multimodality treatment. We assessed specific patterns in PROs and PREs for the following patient characteristics: gender (male versus female), age (<70 years versus ≥70 years), and tumour stage (early versus advanced).

## **Ethics**

The Medical Ethical Committee of the region Arnhem–Nijmegen declared that ethical approval was not necessary.

## **RESULTS**

### **Study population**

A total of 345 patients completed 571 questionnaires containing both the EORTC QLQ-C30 and EORTC QLQ-H&N35 at baseline and at three follow-up moments (Table 1). A total of 71 patients completed the CQI oncology at 12 months after diagnosis (Table 1). The patients were treated in three different HNOs.

### **Patient-reported outcomes**

The global health status (GHS) tended to increase from baseline to 12 months after follow-up for surgery, radiotherapy, and multimodality (Figure 1). However, in the surgery group, the GHS had already increased at 3 months after the last treatment compared to multimodality treatment and radiotherapy alone. Emotional functioning tended to increase at each follow-up moment for all treatment types. In general, a treatment with radiotherapy alone tended to have a major impact

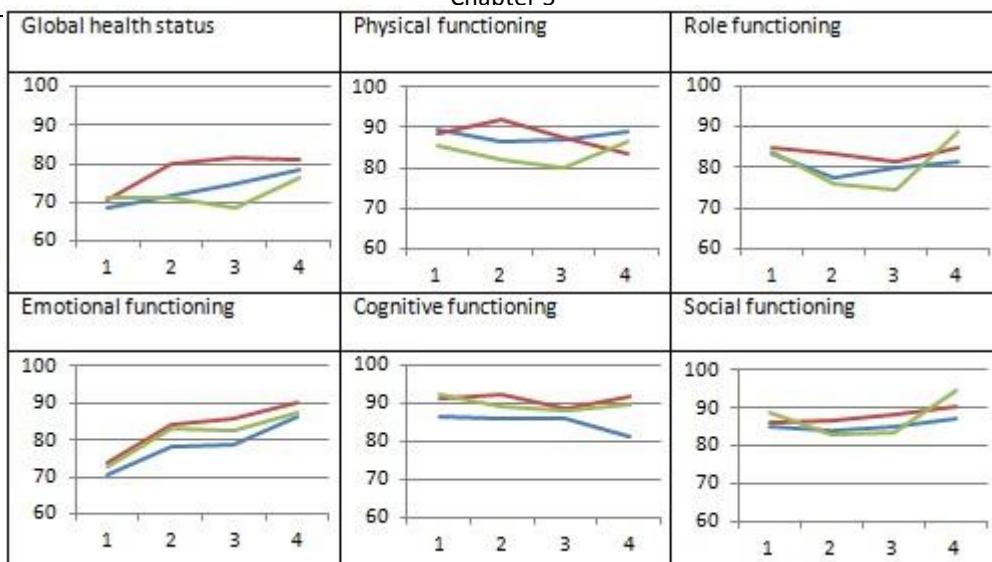
on physical functioning and role functioning up to the first 3 months after the last radiation. Thereafter, these patients had better increases on the functional scales than for the other treatments.

**Table 1.** Characteristics of patients who completed the PROMs and PREMs.

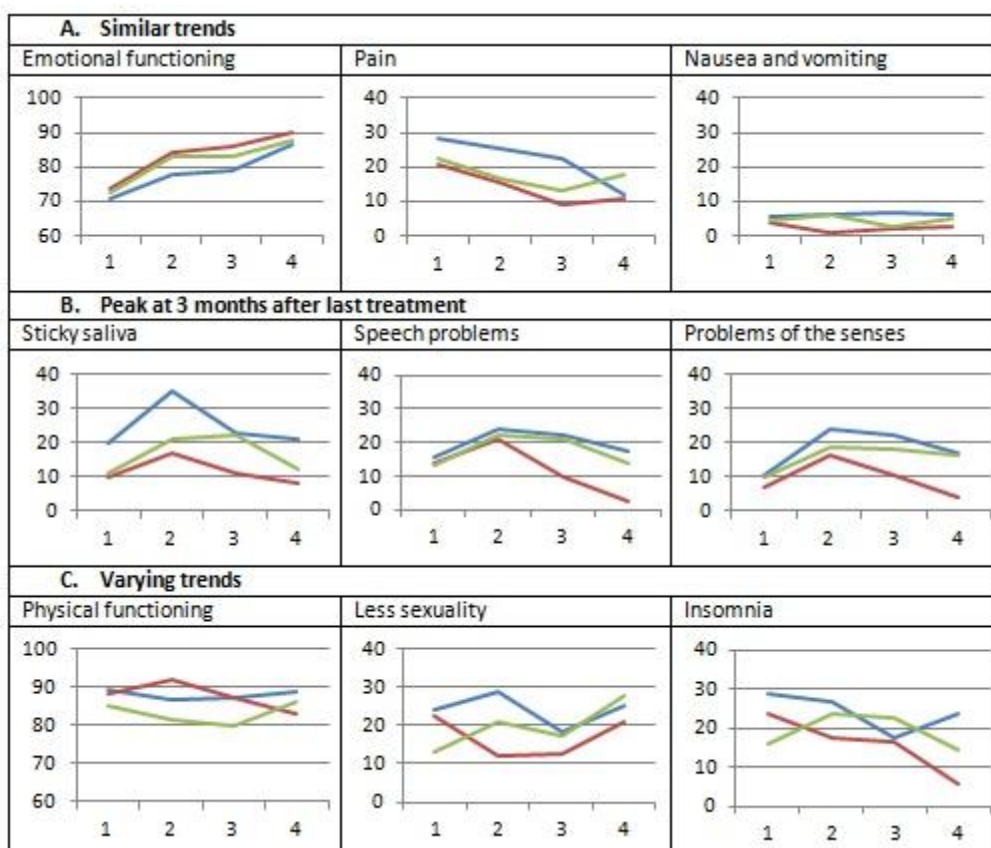
	PROMs			PREMs	
	Monomodality (%)	Multimodality (%)		Monomodality (%)	Multimodality (%)
	Surgery <i>n</i> = 82	RAT <i>n</i> = 117	<i>n</i> = 146	<i>n</i> = 38	<i>n</i> = 33
<b>Median age at start of treatment</b>	67 years	66 years	66 years	68 years	59 years
<b>Gender</b>	Male	78	78	73	73
	Female	22	22	27	27
<b>Tobacco smoking</b>	Never smoker	13	9	18	33
	Former smoker	35	26	40	49
	Current smoker	21	37	28	12
	Data missing	31	28	14	6
<b>Alcohol use</b>	Never drinker	18	16	16	24
	Former drinker	5	3	8	9
	Current drinker	60	60	63	58
	Data missing	17	21	13	9
<b>Performance status</b>	None	4	4	3	6
	Performance status registered	55	48	62	64
	Score 0 (perfect health)	40	40	53	55
	Score > 0	15	8	8	9
	Data missing	45	52	38	36
	Data missing	35	48	35	6
<b>Tumour site</b>	Other	15	13	27	27
	Oral cavity and oropharynx	44	27	47	55
	Larynx and hypopharynx	37	58	21	12
	Data missing	5	6	4	6
<b>Clinical TNM stage</b>	Early (Stage ≤ 2)	63	42	18	21
	Advanced (Stage >2)	12	38	64	61
	Data missing	24	21	18	18
<b>Comorbidity</b>	Score 0	31	37	21	
	Score 2		1		3
	Score 3	9	11	23	15
	Data missing	61	51	57	85

\*RAT = Radiotherapy; TNM = tumour nodes metastasis

**Figure 1.** Global health status and functioning scales from the EORTC-C30 for patients with head and neck cancer



Red, surgery; green, radiotherapy; blue, multimodality treatment. X axis: 1, baseline; 2, 3 months after last treatment; 3, 6 months after last treatment; 4, 12 months after last treatment. Y axis: EORTC-C30 score (0 to 100).



**Figure 2A-C.** Examples of trends in EORTC-C30 and EORTC-H&N35 of patients with head and neck cancer  
Red, surgery; green, radiotherapy; blue, multimodality treatment. X axis: 1, baseline; 2, 3 months after last treatment; 3, 6 months after last treatment; 4, 12 months after last treatment. Y axis: EORTC-C30 and EORTC-H&N35 (0-100).

We distinguished three types of trends: an increasing or decreasing trend, a peak at 3 months after the last treatment, and varying trends (Figure 2A-C). The domain of Emotional functioning

and Pain appeared to increase or decrease for all types of treatment (Figure 2A). The domain Nausea - vomiting showed hardly any variation for either monomodality treatment or multimodality treatment. The domains Sticky saliva, Speech problems, and Problems of the senses each showed a clear peak at 3 months after the last treatment (Figure 2B). For these three domains, a multimodality treatment appeared to give rise to the most problems, followed by radiotherapy alone. The domains Physical functioning, Less sexuality, and Insomnia showed no clear pattern that was similar for all three types of treatment (Figure 2C).

In the domains Dry mouth, Problems with social eating, Problems of the senses, Fatigue, and Speech problems, patients younger than 70 years who received radiotherapy treatment had more problems at 3 months after the last radiation therapy than patients older than 70 years (results not shown). For the next follow-up moments, the problems decreased for patients younger than 70 years and increased for patients older than 70 years. However, the domain Physical functioning showed the opposite; most problems occurred at 3 months after the last treatment for patients older than 70 years.

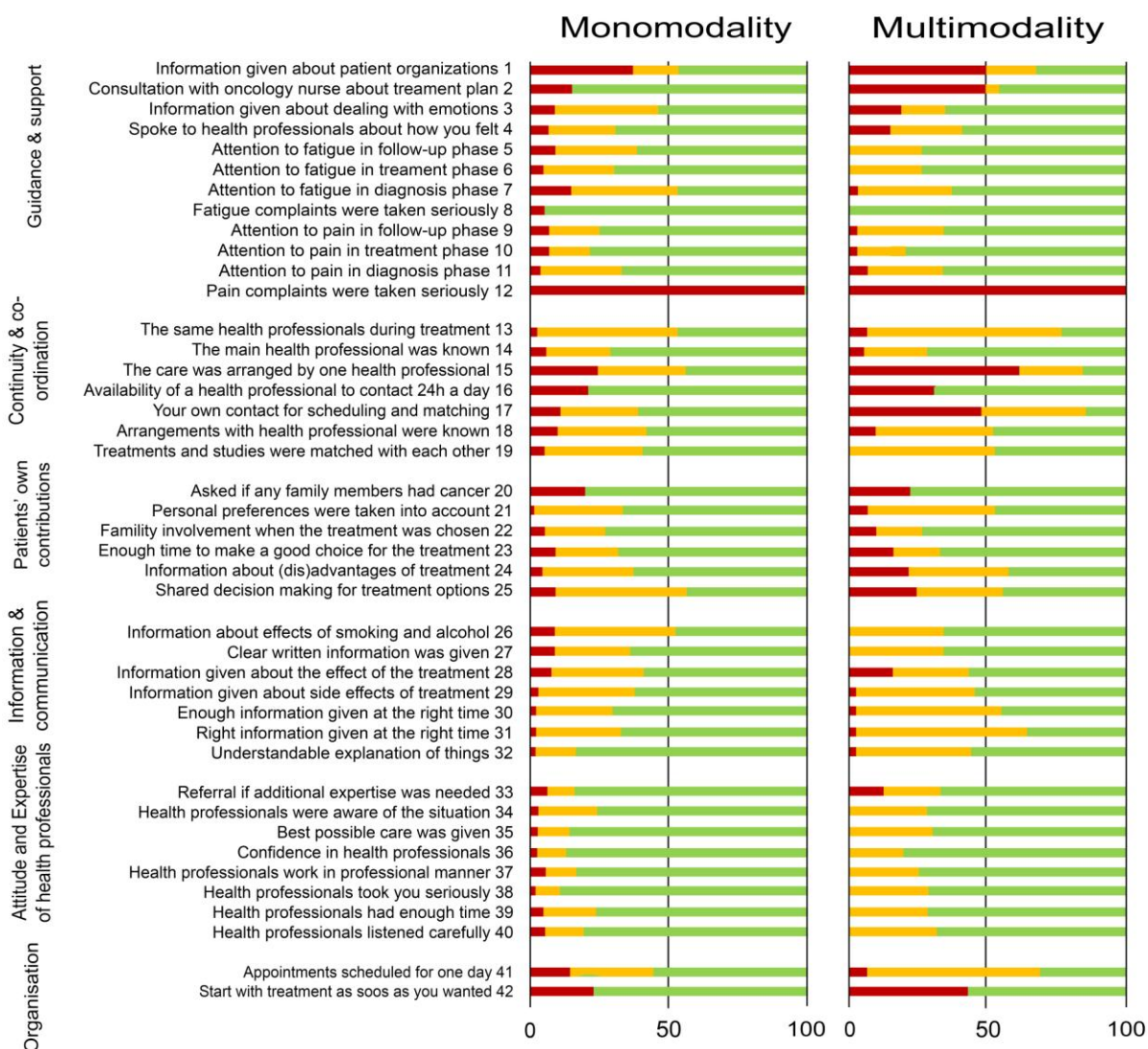
Patients with an advanced tumour stage had more problems than patients with an early stage for radiotherapy alone and for multimodality treatment (results not shown). This was especially the case for Sticky saliva, Pain, Swallowing, and Problems of the senses after multimodality treatment at baseline and 3 months follow-up. The symptoms and functional scales Dry mouth, Problems with social eating, Global health status, Physical functioning, and Role functioning led to more problems or worse functioning for patients with an advanced tumour stage after multimodality or radiotherapy treatment at 3 and 6 months of follow-up.

Differences between male and female patients appeared mainly in the functional scales and less in the symptom scores (results not shown). Men had better scores for role functioning and emotional functioning regarding surgery and radiotherapy alone. Men had better scores after surgery than women in the domain Pain. There were hardly any clinical differences for multimodality treatment.

## Patient-reported experiences

Figure 3 shows the experiences of patients with monomodality treatment and multimodality treatment. In general, patients receiving multimodality treatment mentioned poorer experiences slightly more frequently than patients receiving monomodality treatment did, particularly in the domains Organisation, Attitude of health professionals, Expertise of health professionals, and Continuity & Coordination. For example, the domain Continuity & Coordination scored up to 75% for three questions in the categories Never/Sometimes and Mostly; namely, if care was arranged by one health professional (question 15), if the patient had one contact person in the hospital for scheduling and matching consultations (question 17), and if the patient saw the same health

professionals as much as possible during investigations and treatments (question 13). These questions scored only 55%, 38%, and 52% in the categories Never/Sometimes and Mostly for patients receiving monomodality treatment.



**Figure 3.** Experiences of patients with head and neck cancer receiving monomodality treatment or multimodality treatment. Red, Never/Sometimes; yellow, Mostly; green, Always.

In the remaining domains Information & Communication, Patients' own contributions, and Guidance & Support, most questions showed similar experiences or, more frequently, poorer experiences for patients receiving multimodality treatment than patients receiving monomodality treatment. This was more often true if health professionals informed the patient about patient organisations (question 1), if a consultation with an oncology nurse was arranged to discuss the definitive treatment plan (question 2), if the right information was given at the

right time (question 31), and if information about advantages and disadvantages was given (question 24). However, three questions in the domain Guidance & Support had better scores for patients receiving multimodality treatment, namely, if information about help and guidance in dealing with emotions and practical problems with cancer was given (question 3), if attention was given to fatigue problems in the follow-up phase (question 5), and if attention was given to fatigue problems in the diagnosis phase (question 7). Scores for Never/Sometimes and Mostly were 48%, 30%, and 52% for monomodality treatment, respectively, and 36%, 26%, and 37% for multimodality treatment, respectively. It is interesting that the question whether caregivers took pain seriously (question 12) had a score above 96% in the category Never/Sometimes and Mostly for both treatments.

Regarding patient characteristics, patients 70 years or older had better experiences with healthcare compared to patients younger than 70 years, except for the domain Guidance & Support and the domain Organisation (results not shown). In each domain, patients with an advanced tumour stage had poorer scores for experience with healthcare than patients with an early tumour stage. Women did better in the domains Guidance & Support, Information & Communication, Attitude of health professionals, and Expertise of health professionals than men did.

## DISCUSSION

We aimed to measure PROs and PREs in integrated HNC care to assess how patients feel and how patients experience integrated care. In addition, we assessed differences between monomodality treatment and multimodality treatment to obtain information about specific aspects of different treatment methods to be used for improving care. The PROs showed that functioning and symptoms differ between follow-up moments and type of treatment. In general, patients who received radiotherapy alone had better functioning and fewer symptoms than patients who received multimodality treatment. Patients who underwent surgery tended to have better functional outcomes and fewer symptoms than patients who received radiotherapy. Regarding PREs, patients receiving multimodality treatment mentioned poorer experiences more frequently than those receiving monomodality treatment. This was especially the case in the domains Organisation, and Attitude of health professionals, and Expertise of health professionals. In addition, we assessed different trends for the different patient characteristics of gender, age, and tumour stage.

As expected, our study shows that the type of treatment influences how patients feel and what they experience during the integrated care process. Certain symptoms are specific to the type of treatment and will therefore always come forward; for example, a dry mouth after radiotherapy. However, for non-specific functions, symptoms and experiences, we also expected that multimodality treatment would give poorer results than monomodality treatment since

more alignment, collaboration, and co-ordination is necessary in the healthcare process. Ramaekers and colleagues studied the negative association of complications with lower utility and Visual Analog Scale (VAS) score and shows that adding surgery to radiotherapy (multimodality) decreases the quality of life of HNC patients<sup>31</sup>. In more detail, there are studies that even show that different techniques for radiotherapy or surgery result in different HNC-related symptoms<sup>32,33</sup>. Villaret shows that the quality of life of patients who underwent a surgical reconstruction after being diagnosed with oral cavity cancer decreases dramatically during the first 3 months. Hereafter, it increases. Similar patterns were seen in the functioning scales in this study, but not for symptoms. The explanation is that 48% of the patients also received post-operative radiotherapy or chemo-radiotherapy. In addition, patients completed the questionnaires at follow-up moments after the operation (even though radiotherapy and chemoradiation were given). In our study, patients completed the questionnaires after the last treatment. Probably the patients in Villaret's study had not recovered optimally due to the additional treatments, which adds another dimension to their results.

Previous studies show an association between patient characteristics and quality of life<sup>24,34</sup>. Taher et al. show a negative effect on quality of life for females above the age of 60 years old with a clinical stage of III and IV compared to males under the age of 60 years old with a clinical stage of I and II<sup>34</sup>. Kucuk and colleagues show that symptoms of the EORTC H&N35 were significantly higher in patients with an advanced stage than in patients with an early stage. Although we only analysed frequencies for these characteristics, both studies show results similar to those of our study. In the future, more data will be available for studying the association of PROs and PREs versus patient characteristics.

Regarding outcomes, previous literature shows that integration of PROs into the routine care increases survival significantly for patients with cancer compared to usual care<sup>13</sup>. This increases the importance of monitoring PROs in clinical practice. In the DHNA, the online system can be expanded for health professionals so that they can use the PROs and PREs in their consultations.

## **Strengths and limitations**

Strengths of this study were the possibility to analyse PROs and PREs in different subgroups of patients and targets for quality improvement on specific parts of the healthcare process where problems were encountered. We performed an observational study with 345 patients who completed the PROMs and 71 patients who completed the PREMs. The number of patients who completed the PREM is equal to only 20% of the patients who completed the PROMs. One explanation for this is that a patient needs to be further in the follow-up phase to complete a PREM than for the times when the PROMs have to be completed. In addition, for the PROMs, we see a decrease in the response rate when the period of treatment becomes longer. This might be another explanation for a low response rate for the PREMs. Since the patient populations for

both PROMs and PREMs seem similar (Table 1), we do not expect bias. Apart from frequencies, no statistical analyses were done because the number of patients for each treatment group at each follow-up moment was sometimes less than 20. There were three reasons: non-response of patients after the first questionnaire, not all patients were able to complete a PRO at each follow-up moment, and not all patients had reached the time of 1 year of follow-up after the last treatment. When more data become available in the future, possible differences can be tested for various follow-up moments and different treatments using statistics. Further, associations between PROs and PREs can be studied by analysing the data of patients who completed both PROMs and PREMs. Patients were included from three different specialised hospitals. When more data is available, differences between these hospitals and the influence of patient characteristics can be analysed. We generalised different treatment methods by categorising them as monomodality or multimodality.

## Conclusion

In conclusion, a patient who undergoes multimodality treatment tends to experience a healthcare process that is less well-organised, achieves poorer functional scores, and has more symptoms than patients who undergo monomodality treatment. Given the greater incidence of symptoms and greater loss of function in patients after multimodality treatment, the follow-up phase should be directed to rehabilitation by restoring function and decreasing symptoms. For both monomodality and multimodality treatments, monitoring PROs and PREs should become easier and results should be more visible for health professionals to act on.

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### Feedback preferences of patients, professionals and health insurers in integrated head and neck cancer care



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## ABSTRACT

**Background:** Audit and feedback on professional practice and healthcare outcomes are the most often used interventions to change behaviour of professionals and improve quality of healthcare. However, limited information is available regarding preferred feedback for patients, professionals and health insurers.

**Objective:** Investigate the (differences in) preferences of receiving feedback between stakeholders, using the Dutch Head and Neck Audit as an example.

**Methods:** A total of 37 patients, medical specialists, allied health professionals and health insurers were interviewed using semi-structured interviews. Questions focussed on: 'Why', 'On what aspects' and 'How' do you prefer to receive feedback on professional practice and healthcare outcomes?

**Results:** All stakeholders mentioned that feedback can improve healthcare by creating awareness, enabling self-reflection and reflection on peers or colleagues, and by benchmarking to others. Patients prefer feedback on the actual professional practice that matches the healthcare received, whereas medical specialists and health insurers are interested mainly in healthcare outcomes. All stakeholders largely prefer a bar graph. Patients prefer a pie chart for patient-reported outcomes and experiences, while Kaplan–Meier survival curves are preferred by medical specialists. Feedback should be simple with firstly an overview, and 1–4 times a year sent by e-mail. Finally, patients and health professionals are cautious with regard to transparency of audit data.

**Conclusions:** This exploratory study shows how feedback preferences differ between stakeholders. Therefore, tailored reports are recommended. Using this information, effects of audit and feedback can be improved by adapting the feedback format and contents to the preferences of stakeholders.

## INTRODUCTION

Much effort has been devoted to improve professional practice and outcomes in healthcare during the past decades, unfortunately with varying effects. A widely used strategy to improve healthcare is 'audit and feedback'<sup>1,2</sup>, defined as any summary of clinical performance of healthcare over a specified period of time, given in a written, electronic or verbal format, offering professionals performance information and motivation to improve<sup>3</sup>.

One of the methods to derive the information for audit and feedback is using quality indicators<sup>4,5</sup>. Quality indicators are aimed at detecting suboptimal care either in structure or process (e.g. the percentage of patients discussed in multidisciplinary team meetings), or outcomes (e.g. patient-reported outcomes [PROs] and experiences [PREs]). They can be used as a tool to guide the process of quality improvement in healthcare<sup>6</sup>.

Although positive effects of audit and feedback have been reported, namely decreased duration of hospital stay<sup>7</sup> and decreased mortality rates<sup>8</sup>, this improvement strategy has not been found to be consistently effective<sup>2,9-12</sup>. So far, research has focussed on increasing the effectiveness of feedback, for example by including a worksheet in the feedback to facilitate goal setting<sup>13</sup> and timing of audit and feedback<sup>3,14,15</sup>. Audit and feedback researchers have recommended a shift towards comparative effectiveness studies, evaluating how and when audit and feedback components will work, rather than its overall effectiveness<sup>16</sup>.

The format of feedback may significantly affect the interpretation of data<sup>17-19</sup>. However, there is only limited information available regarding formats of feedback, for example on how to summarize and display results of outcome measures in the best way<sup>20-22</sup>. Furthermore, implementation of audit and feedback is likely to be more effective when feedback messages can influence barriers to change behaviour. These barriers appear to differ across individuals<sup>23</sup>. In addition, most audit and feedback interventions use written or graphical feedback in one uniform format for all recipients<sup>7</sup>. This will surely not meet the preferences of all recipients, and effects will be low if recipients do not understand the feedback. In developing feedback formats, it is therefore necessary to involve all stakeholders receiving feedback, so as to guarantee that the presentation of feedback meets their preferences<sup>20,24</sup>.

In healthcare systems worldwide, various stakeholders use feedback on quality indicators for different purposes, such as: (1) patients, who are the recipients of healthcare and for whom feedback on PROs and PREs can be used to improve and monitor their own or others' health and healthcare pathways; (2) medical specialists, who deliver healthcare and for whom the feedback on their own delivered care may improve healthcare; (3) allied health professionals, including nurses, who have a similar role as medical specialists, although restricted to allied healthcare; and (4) health insurers, who search for quality information suitable to create differences in quality of care levels as a basis for their contracting. We hypothesize that by adapting feedback to the preferences of these different stakeholders, they will better respond to the information delivered, and more improvement in effects of audit and feedback could be possible.

In this exploratory study, we aim to investigate the preferences of various stakeholders on receiving feedback, with the Dutch Head and Neck Audit (DHNA) as an example. Head and neck cancers (HNCs) are heterogeneous both biologically as well as in clinical behaviour, and they grow relatively fast in an anatomically and functionally complex area<sup>25,26</sup>. Patients often have problems with speech, swallowing and physical disfiguration due to treatment<sup>27,28</sup>, requiring the collaboration of both medical specialists and allied health professionals. Therefore, high-quality integrated care for patients with this type of tumour is needed<sup>29,30</sup>. The DHNA uses quality indicators to measure the quality of integrated care for patients with HNC within 14 Dutch hospitals<sup>31</sup>. By investigating the preferences on feedback of all four stakeholders in the DHNA (medical specialists, allied health professionals, patients and health insurers), including 'Why', 'On what aspects' and 'How' do you prefer to receive feedback on professional practice and healthcare outcomes, this study can provide useful tools to potentially improve quality of care by adapting the feedback format and contents to stakeholders' preferences. This can serve as an example for other integrated oncologic care pathways where audit and feedback will be used or, unfortunately, is still less effective.

## **METHODS**

### **Study design**

The first author conducted semi-structured interviews with four stakeholders to investigate preferences on feedback using the 'consolidated criteria for reporting qualitative research' checklist (COREQ)<sup>32</sup>. Interviews were transcribed verbatim and qualitatively analysed by the first and third author.

### **Setting**

Approximately 3,000 patients are diagnosed yearly with HNC in the Netherlands<sup>33</sup>. HNC care is centralized in 14 hospitals: eight Head and Neck Oncology Centres (HNOCs) and six affiliated centres. The affiliated centres have committed themselves to using the same treatment protocols as the related HNOC. The various medical specialists and allied healthcare professionals involved in HNC care are united in two national foundations: one for medical specialists (NWHHT) and one for allied health professionals (PWHHT). Previously, there were two Dutch patient associations: '*Stichting Klankbord*' and '*NSVG*'. The former represented all patients with HNC, the latter only laryngectomised patients. Currently, they collaborate in one Dutch patient association called '*patiëntenvereniging Hoofd-hals*'. In the Netherlands, there are four major health insurers as well as several smaller companies. In 2014, a quality registration was set up to measure the quality of integrated HNC care, using quality indicators selected by the four stakeholders<sup>31</sup>.

## Participants

Four different groups of stakeholders were interviewed about their preferences. Research shows that 13–15 interviewees are usually sufficient to reach data saturation (the point at which no new information is mentioned in interviews)<sup>34</sup>. Therefore, at least 13 persons were invited for each stakeholder group. However, only the four major health insurers were invited. A patient panel (including the chairmen of both patient associations) that participated in a previous study was asked by e-mail to participate again<sup>35</sup>. A letter with additional information about the research methods and an informed consent form were handed over to the patients at a meeting prior to the interview. The location for the personal appointment was either at their home, their work or at the hospital. Medical specialists and allied health professionals and nurses, belonging to the national foundations, were invited to participate in an interview, either by telephone or in person. We aimed to interview at least one professional of each profession (radiation oncologist, medical oncologist, oral and maxillofacial surgeon, otorhinolaryngologist, speech therapist, physiotherapist, dietician, oral hygienist and nursing consultant) involved in HNC care. We contacted the four major health insurers by e-mail, to ask whether they would be willing to participate in an interview, either by telephone or in person. Persons approached were specialised in healthcare purchasing policy, innovation and advice or innovation and quality. Prior to an interview by telephone or a meeting, the professionals, patients and health insurers received a document with examples of the type of graphs to be discussed (see Result section Table 6, first column). In this article, the term 'professionals' will be used when referring to medical specialists together with allied health professionals, and 'allied health professionals' refers to both allied health professionals and nurses.

## Data collection

Each interview took approximately 20–30 minutes and was audio-recorded. Moreover, all patients signed informed consent forms, while each interviewee received the same questions. Questions focussed on three topics: (1) 'Why do you prefer to receive feedback on professional practice and healthcare outcomes?', e.g. reasons for feedback at an individual level, hospital level and national level for indicators on outcome, process and structure; (2) 'On what aspects would you prefer to receive feedback regarding professional practice and healthcare outcomes?', e.g. interest in specific indicators; (3) 'How do you prefer to receive feedback on professional practice and healthcare outcomes?', e.g. frequency, timing, report form, type of graph preferred and transparency, e.g. whether patients prefer to receive national average scores on PROs and PREs and whether results of quality of care in hospitals can become public. In addition, the interviews with patients were focussed particularly on the PROs and PREs with regard to questioning healthcare outcomes, since patients had a better understanding of the feedback on these questions compared with feedback on, for example, survival. Questions for the health insurers focussed merely on the goal of feedback, since they will use feedback in a different way



compared with patients and health professionals. Different graph types were selected from feedback reports used in other research or found on the Internet, for example a bar graph, pie chart, line graph, point graph, area graph, box plot, Kaplan–Meier graph or a funnel plot. Moreover, a distinction was made between graphs for outcome indicators such as survival and PROs and PREs, since, in general, different graphs are used for both types of data.

### **Analysis of interviews**

Interviews were transcribed verbatim and qualitatively analysed using ATLAS.ti (version 7)<sup>36</sup>. The first two interviews of each stakeholder group were coded independently by the first and third author (LO and TV) (female, MSc, first author; male MSc, third author; both working in the same research institute). All identified items were compared and discussed until consensus was reached. The remaining interviews were coded by the first author and checked by the third author to enhance the reliability and validity of the results. The same two researchers then categorised all identified items into the interview topics. Subcategories of all codes dealing with the same subject were made by the two researchers within each category, resulting in a code tree. For example, a division into three subcategories was made within the category ‘Why do you prefer to receive feedback?’: individual level, hospital level and national level. Or, in the category ‘How do you prefer to receive feedback’, all codes regarding distribution of the report were compiled, thereby forming a subcategory. Disagreement was discussed between the two researchers and if necessary with the last author (RH) (female, PhD, last author) until consensus was reached.

## **RESULTS**

### **Study population**

For the patients as stakeholders, a response rate of 76% was reached, since three patients did not participate due to time constraints or did not respond to the e-mail or reminder. A total of eight patients and the chairmen of both patient associations participated in the semi-structured interviews, all in person (Table 1).

The medical specialists and allied health professionals had a response rate of 94% and 69%, respectively. Reasons for not participating were time constraints, the person did not belong to the board of the national foundation for allied health professionals anymore or the person did not respond to the e-mail or the reminder. A total of 15 medical specialists ( $n = 15$ ) and nine allied health professionals participated in an interview ( $n = 9$ ), either by telephone ( $n = 18$ ) or in person ( $n = 6$ ) (Table 2).

**Table 1.** Characteristics of ten participating patients\*.

Variable		<i>n</i>
Age, years	Mean	59.4
Sex, <i>n</i>	Female	4
	Male	6
Education level, <i>n</i> *	Medium and lower	4
	High	5
Type of tumour, <i>n</i> *	Larynx	4
	Oral cavity	5
Type of treatment, <i>n</i> *	Operation	2
	Chemoradiation	1
	Operation & radiotherapy	5
	Operation & chemoradiation	1
Year of diagnosis*		1997–2013

\* Exclusion of the chairman of a patient association, who was not a patient.

**Table 2:** Characteristics of 24 participating professionals.

Variable		<i>n</i>
Dutch Head and Neck Society		15
	Head and Neck Oncology Centres	10
	Affiliated centres	5
Dutch Head and Neck Allied Health Professionals Group		9
	Head and Neck Oncology Centres	7
	Affiliated centres	2

The professions of these members included three radiation oncologists, two medical oncologists, five oral and maxillofacial head and neck surgeons, five otorhinolaryngologist head and neck surgeons, one speech therapist, two physiotherapists, two dieticians, two oral hygienists and two nursing consultants. Furthermore, the health insurers had a response rate of 75%, since one health insurer was not willing to participate. In total, three health insurers participated in an interview, either by telephone ( $n = 1$ ) or in person ( $n = 2$ ).

## Preferences

Tables 3, 4, 5 and 6 present an overview of the preferences of patients, professionals, and health insurers regarding the three topics. In the following paragraphs, the preferences have been summarised. In addition, Figure 1 presents quotes from different stakeholders on the main research questions.

**Table 3.** Why do you prefer to receive feedback?

Subject	Patient	Medical specialist	Allied health professional	Health insurer
Feedback on indicators*	<p>At an individual level – Patients:</p> <ul style="list-style-type: none"> <li>+ Patients are curious</li> <li>+ Feedback is useful for future patients</li> <li>+ To give patients more information about the healthcare process</li> <li>+ To give patients the opportunity to choose the best hospital (although some patients state that there is no option to choose, due to distance and other factors and the fact that patients prefer a treatment first)</li> <li>– Patients may not be interested</li> <li>– Feedback is not of any value to the patient</li> <li>– Patients might regret their decision for their treatment in that specific hospital if data become transparent/public</li> </ul> <p>At an individual level – Professionals:</p> <ul style="list-style-type: none"> <li>+ To give doctors more insight into the healthcare process; an eye-opener</li> <li>+ A way to improve healthcare instead of a threat to the professional</li> </ul> <p>At a hospital level:</p> <ul style="list-style-type: none"> <li>+ To motivate professionals to perform better</li> <li>+ To monitor healthcare in hospitals</li> </ul>	<p>At an individual level – Patients:</p> <ul style="list-style-type: none"> <li>– Feedback can result in wrong interpretations by patients</li> <li>– Patients are possibly not interested in indicators</li> </ul> <p>At an individual level – Professionals:</p> <ul style="list-style-type: none"> <li>+ To become better aware of the outcomes</li> <li>– Feedback can result in wrong interpretations by professionals</li> </ul> <p>At a hospital level:</p> <ul style="list-style-type: none"> <li>+ To see how other professionals in your hospital function; to keep everyone focussed</li> <li>+ Feedback as a stimulating factor to improve performance</li> <li>+ To know where the weak points are in your hospital</li> <li>+ To better organise the healthcare process</li> <li>+ Important to develop improvement plans: first let the hospitals change within their hospital and improve healthcare</li> <li>+ Important to put quality on the agenda in your hospital in order to pay more attention to feedback</li> </ul> <p>At a national level:</p> <ul style="list-style-type: none"> <li>+ To compare all hospitals with each other</li> <li>+ To increase national healthcare</li> <li>+ To improve outcomes</li> </ul>	<p>At an individual level – Patients:</p> <ul style="list-style-type: none"> <li>+ Patient can engage in the conversation with professionals if the delivered care does not meet the conditions</li> <li>– Feedback can result in wrong interpretations by patients</li> </ul> <p>At an individual level – Professionals:</p> <ul style="list-style-type: none"> <li>+ To see how your colleagues are working</li> <li>+ To create more awareness in order to deliver good healthcare as a professional</li> <li>+ To pay attention to indicators, since these are easily forgotten</li> <li>– Feedback can result in wrong interpretations by professionals</li> <li>– No interest in results of indicators</li> </ul> <p>At a hospital level:</p> <ul style="list-style-type: none"> <li>+ To see how well your hospital is functioning and from which hospital you can learn</li> <li>+ To see which processes work in other hospitals</li> <li>+ Feedback gives tools to engage conversations with colleagues</li> <li>+ To put pressure on the board of directors</li> <li>+ Important to create a structure where improvement is possible and to develop improvement plans</li> <li>+ Put quality on the agenda in your hospital</li> </ul>	<p>At an individual level – Patients:</p> <ul style="list-style-type: none"> <li>+ To represent patients' interests</li> <li>+ To inform patients where best care is delivered.</li> </ul> <p>At an individual level – Professionals:</p> <ul style="list-style-type: none"> <li>+ To engage in conversation between professional and health insurer</li> </ul> <p>At a hospital level:</p> <ul style="list-style-type: none"> <li>+ To improve quality of care</li> <li>+ To purchase by value</li> <li>+ To engage in conversations with hospitals and to take actions if the care delivered is of inferior quality, not to punish hospitals</li> <li>+ To measure quality of integrated healthcare instead of measuring quality of separate parts of the healthcare pathway</li> <li>+ Put quality on the shared agenda of healthcare providers and health insurers</li> </ul> <p>At a national level:</p> <ul style="list-style-type: none"> <li>+ To develop demands to improve quality of care</li> <li>+ To compare hospitals for care procurement</li> <li>+ To set up best practices</li> <li>+ To ensure that hospitals do not see the health insurance company as the enemy</li> </ul>

- At a national level:
  - + To compare hospitals with each other and visualise the differences, although some patients consider this to be a difficult task
  - + Important to act upon the feedback reports
- nationwide
  - Feedback is just a small part of healthcare; healthcare itself is about the whole figure
- At a national level:
  - + To compare and to improve together
  - + To improve or develop (new) options for treatment

Feedback on PROs and PREs

- |  |   |   |   |
|--|---|---|---|
| <ul style="list-style-type: none"> <li>At an individual level – Patients:           <ul style="list-style-type: none"> <li>+ Patients are curious</li> <li>+ To reflect and create awareness for the patient</li> <li>+ To engage in the conversation with relatives, peers and professionals</li> <li>– Patients may not be interested</li> <li>– Feedback might be hard to deal with</li> <li>– Feedback about your own experiences and quality of life makes it less useful</li> </ul> </li> <li>At an individual level – Professionals:           <ul style="list-style-type: none"> <li>+ To create more empathy in professionals towards patients</li> <li>+ Feedback might be more relevant and convenient for the nurse instead of the doctor</li> <li>– Feedback can influence the patient–professional relation</li> </ul> </li> <li>At hospital level:           <ul style="list-style-type: none"> <li>+ To improve quality of healthcare according PROs and PREs</li> </ul> </li> <li>At national level:           <ul style="list-style-type: none"> <li>+ To give insight into which hospital performs best on PROs and PREs</li> </ul> </li> </ul> | <ul style="list-style-type: none"> <li>At an individual level – Patients:           <ul style="list-style-type: none"> <li>+ Important to give all results back to the patient, also your own PROs and PREs</li> </ul> </li> <li>At an individual level – Professionals:           <ul style="list-style-type: none"> <li>+ Interesting to see results of PROs through time</li> </ul> </li> <li>At a hospital level:           <ul style="list-style-type: none"> <li>+ Use PROs and PREs for research on prognostic factors</li> <li>+ To improve by knowing how your hospitals scores on PROs and PREs</li> </ul> </li> <li>At a national level:           <ul style="list-style-type: none"> <li>+ To benchmark with other hospitals</li> </ul> </li> </ul> | <ul style="list-style-type: none"> <li>At an individual level – Patients:           <ul style="list-style-type: none"> <li>+ To compare scores of patients on PROs and PREs</li> </ul> </li> <li>At an individual level – Professionals:           <ul style="list-style-type: none"> <li>+ It is also about ‘how’ the patient lives instead of ‘if’ the patient lives</li> </ul> </li> <li>At a hospital level:           <ul style="list-style-type: none"> <li>+ To improve by knowing how your hospitals scores on PROs and PREs</li> </ul> </li> <li>At a national level:           <ul style="list-style-type: none"> <li>+ To compare scores of patients on PROs and PREs within a healthy population</li> </ul> </li> </ul> | <ul style="list-style-type: none"> <li>At an individual level – Patients:           <ul style="list-style-type: none"> <li>+ To send patients to the best performing hospital</li> </ul> </li> <li>At an individual level – Professionals:           <ul style="list-style-type: none"> <li>+ To better know what the patient wants</li> </ul> </li> <li>At a hospital level:           <ul style="list-style-type: none"> <li>+ To use patient experiences to improve quality of care in hospitals</li> </ul> </li> <li>At an national level:           <ul style="list-style-type: none"> <li>+ PROs and PREs are part of the healthcare delivered</li> </ul> </li> </ul> |
|--|---|---|---|



### ***Why do you prefer to receive feedback?***

#### **Feedback on professional practice & healthcare outcomes**

In general, all stakeholders prefer feedback on professional practice and healthcare outcomes (Table 3). The main reason mentioned was that feedback can improve healthcare, either at an individual level, hospital level or national level. Feedback can create awareness. It can also be a method for reflection on yourself and on peers or colleagues.

Feedback can also be used to benchmark and improve healthcare with all healthcare providers together. Stakeholders agree that it is important to act upon feedback, either by developing improvement plans or by putting the feedback on the agenda as a start. Both actions will result in more attention to the use of feedback in the hospital. Additionally, feedback can engage quality of care discussions among and with professionals, patients and health insurers about the care delivered and the experiences of all parties involved. All four stakeholders agree that patients might not be interested in or might not understand the feedback on professional practice. In addition, healthcare professionals themselves mentioned that not all healthcare professionals would be able to understand the feedback properly.

Health insurers specifically stated that it is not their aim to judge hospitals for the good work they deliver, but to apply feedback as a discussion tool in their interactions with care providers. Health insurers consider feedback to be a necessary tool to improve care for the patient (e.g. by informing the patient and representing their interest based on the feedback). In comparison, professionals consider feedback to be a method to improve care together with the patient.

#### **Feedback on PROs and PREs**

The main reason for patients to want to receive feedback on PROs and PREs is to be able to engage in the discussions with peers or professionals regarding their quality of life, experiences and received care.

Medical specialists see the PROs and PREs as another way of benchmarking and improving healthcare. Allied health professionals mention that feedback on PROs and PREs are of particular interest, since they are about 'how' the patient lives instead of 'whether' the patient lives for a longer period. For health insurers, PROs and PREs form a part of the outcome indicators and are necessary to measure quality; patient experiences are necessary to improve healthcare.

### ***On what aspects do you prefer to receive feedback?***

Patients would prefer to receive feedback on the professional practice that matches their healthcare pathway; for example, the patient does not want to receive feedback on the professional practice of the physiotherapist if the patient did not receive any physiotherapy at all (Table 4). Medical specialists and health insurers alike mention that healthcare outcomes are

most relevant when they can be compared with the aspects of professional practice, because they deal with the effect of the treatment.

In contrast with medical specialists, allied health professionals mention more frequently that they are more interested in feedback on the professional practice of their own discipline. However, both groups agree that feedback on all health outcomes and aspects of professional practice is needed, since they also form part of the healthcare pathway of the patient.

**Table 4.** On what aspects do you prefer to receive feedback?

Subject	Patient	Medical specialist	Allied health professional	Health insurer
Interest in specific indicators	<ul style="list-style-type: none"> <li>• Interest in healthcare indicators that match the care received by the patient</li> <li>• Interest in indicators that are considered to be relevant for the patient</li> <li>• Feedback on all indicators to find out whether you missed specific care</li> </ul>	<ul style="list-style-type: none"> <li>• No consensus on content of indicators: interested in all indicators on one hand, or only interested in specific outcome indicators on the other hand</li> </ul>	<ul style="list-style-type: none"> <li>• Interested in indicators of allied health professionals; the remaining indicators are mainly for information (they also mentioned the relevance of receiving feedback on all indicators since they are part of one patient-care pathway)</li> </ul>	<ul style="list-style-type: none"> <li>• Mainly interested in outcome indicators. Process indicators are necessary to monitor the processes that underlie the outcome indicators</li> </ul>

### ***How do you prefer to receive feedback?***

#### **Frequency and timing**

Patients prefer to receive feedback when the specific health outcomes and aspects of professional practice have become relevant in their disease process. They prefer to receive this feedback by e-mail or through a patient portal. In terms of frequency, patients mentioned that, for all indicators (including PROs and PReS), feedback once a year would be sufficient (Table 5). Patients would prefer to receive feedback for the first time after the diagnostic phase, because then their stress level will be lower compared with during the diagnostic phase.

Both medical specialists and allied health professionals agree that feedback should be given more often in the start-up phase of a quality registration. In this way, users will get used to receiving feedback and will act on it.

Medical specialists and allied health professionals differ on the frequency of feedback: medical specialists prefer to receive feedback on process indicators (1–4 times a year) more often compared with outcome indicators (1–2 times a year). However, for allied health professionals, this is exactly the opposite.

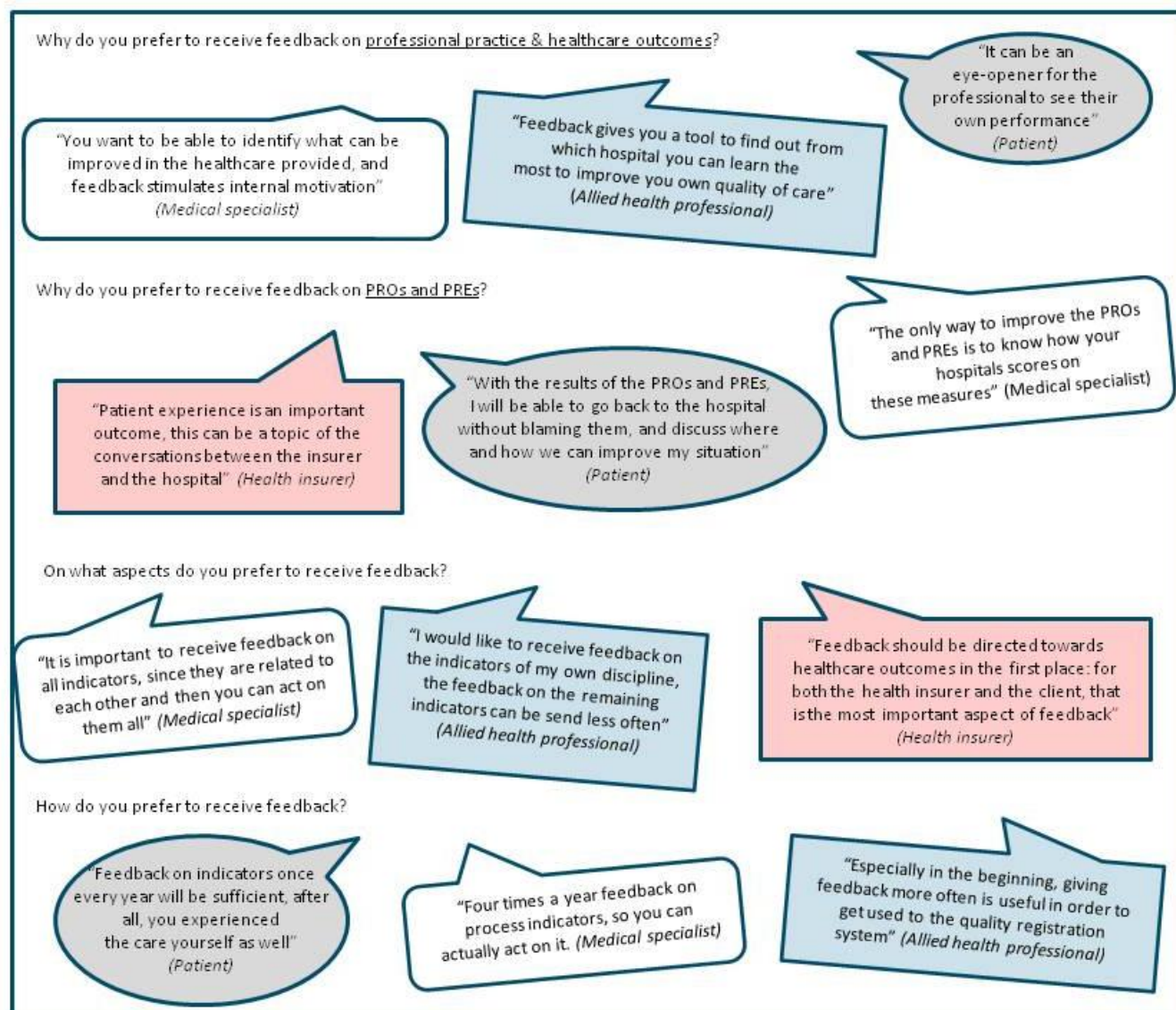


Figure 1 Quotes from different stakeholders on the main research questions.

### Report form

Patients mentioned that feedback should be well balanced and an explanation of the figure or graph should be given. Furthermore, patients mention that average scores of how all hospitals perform on professional practice might be of more interest for professionals and patient associations. With regard to average scores of PROs and PREs, patients mention that it gives them an insight where they stand, as well as possibly giving a boost. On the other hand, information about the average quality of life of other patients might result in insecure or discouraging feelings of patients regarding their own care status.

Professionals agree that the report should be simple as well as giving an overview of the indicators, followed by more in-depth information. In addition, they are all in doubt about displaying average scores or specific scores of hospitals in public. They fear that it could result in

reputational damage when the hospital is pictured as a lesser-performing hospital. Professionals agree that feedback should preferably be given by e-mail.

In contrast to medical specialists, allied health professionals prefer to receive the indicators of their own discipline first, followed by the remaining indicators. In addition, allied health professionals would prefer a meeting around the feedback with more background information. Medical specialists prefer to discuss feedback within their hospital before asking for more background information.

Furthermore, prior to giving feedback on PROs and PREs to patients, medical specialists feel that professionals should question the preferences of the patient regarding receiving their own results or the results of the general population. Professionals should also ask patients whether results on PROs and PREs might be consulted by professionals.

### **Transparency**

Patients and professionals alike are cautious about transparency of data. They are worried about the quality of data and the risk of misinterpretation. Medical specialists suggest organising a committee to decide on issues concerning transparency. In contrast, allied health professionals are in favour of making data public and have less stringent requirements for making data public compared with medical specialists. Health insurers mention that they feel a duty to take responsibility to the population. In order to improve care, it is important to visualise delivered care.

### **Type of graph for feedback on indicators**

Patients mentioned that feedback figures for professional practice are difficult to read for patients in general (Table 6). In contrast, figures for health outcomes are easier to read for patients. Professionals also confirm that patients might not be able to read the feedback on health outcomes and professional practice.

For both health outcomes and professional practice, patients as well as professionals prefer bar graphs since they are easy to read. Other preferred graphs for medical specialists are Kaplan–Meier graphs and box plots for survival indicators and process indicators, respectively. Allied health professionals mention that box plots, Kaplan–Meier graphs and funnel plots give a less clear overview and are more difficult to interpret.

### **Type of graph for feedback on PROs and PREs**

Patients mention that figures for this kind of feedback are easier to read compared with figures for process and structure indicators (Table 6). Patients prefer both a pie chart and a bar graph. In general, patients prefer a figure over plain text. Professionals have a slight preference for a pie chart compared with a bar graph.



**Table 5.** How do you prefer to receive feedback?

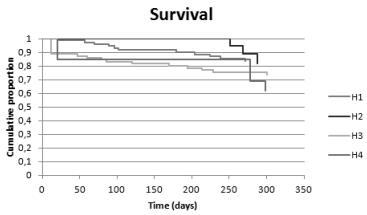
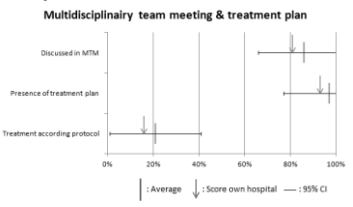
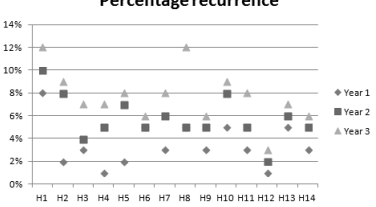
Subject	Patient	Medical specialist	Allied health professional	Health insurer*
Frequency and timing	<p>General:</p> <ul style="list-style-type: none"> <li>Do not give feedback on PROs and PREs too often</li> </ul> <p>Frequency:</p> <ul style="list-style-type: none"> <li>Indicators: once a year</li> <li>PROs/PREs: once a year</li> </ul> <p>Timing:</p> <ul style="list-style-type: none"> <li>Either before treatment or after the diagnostic phase (there is more stress during the diagnostic phase)</li> <li>When the indicators are relevant in the healthcare process</li> </ul>	<p>General:</p> <ul style="list-style-type: none"> <li>Preference for receiving more feedback at the beginning</li> <li>Preference for receiving feedback more often when severe deviations in the data appear</li> </ul> <p>Frequency:</p> <ul style="list-style-type: none"> <li>Process indicators: 1–4 times a year (depending on the possibility of improving in the meantime)</li> <li>Outcome indicators: 1–2 times a year</li> </ul>	<p>General:</p> <ul style="list-style-type: none"> <li>In the beginning, feedback could be given more often</li> </ul> <p>Frequency:</p> <ul style="list-style-type: none"> <li>Process indicators: 1–2 times a year</li> <li>Outcome indicators: 2–4 times a year</li> </ul>	
Report method	<p>General:</p> <ul style="list-style-type: none"> <li>Figures with an explanation of the content and 'how to read'</li> <li>Dosing of the amount of information in smaller parts</li> <li>Keep the target audience in mind (e.g. colour blind, use of medical terms, level of degree)</li> </ul> <p>Use of average scores:</p> <ul style="list-style-type: none"> <li>Give feedback with average national scores on the PROs and PREs, but be aware of consequences: <u>Positive:</u> give insight into where you stand, give a boost and lean on results of other patients</li> <li><u>Negative:</u> insecure or discouraging feelings</li> <li>National average scores on indicators of more interest for patient organisations and professionals</li> </ul>	<p>General:</p> <ul style="list-style-type: none"> <li>Find a balance between giving feedback and giving too much information</li> <li>Give an overview of the results first, followed by the details</li> <li>Present it in such a way that one can easily understand without explanation</li> </ul> <p>Use of average scores:</p> <ul style="list-style-type: none"> <li>Give feedback on own scores compared with the average score, the best hospital and the worst hospital when data will be presented anonymously</li> <li>Give the scores of all hospitals including national average scores, the best and the worst performing hospital</li> </ul> <p>Distribution of feedback:</p> <ul style="list-style-type: none"> <li>Feedback by e-mail</li> <li>First, the hospitals can try to work it out on their own, then they can ask</li> </ul>	<p>General:</p> <ul style="list-style-type: none"> <li>Keep it simple</li> <li>Give an overview of own indicators first, followed by the remaining indicators</li> </ul> <p>Use of average scores:</p> <ul style="list-style-type: none"> <li>Give feedback with the scores of each hospital; use of average scores depends on the goal of the feedback</li> <li>Give feedback on own scores compared with the national average scores to see how your hospital is functioning, since one prefers not to be presented as a 'bad' hospital</li> </ul> <p>Distribution of feedback:</p> <ul style="list-style-type: none"> <li>Feedback by e-mail</li> <li>A meeting in the hospital organised by the investigator is preferred for more background information and explanation of the results</li> </ul>	

	<p>Distribution of feedback:</p> <ul style="list-style-type: none"> <li>• Feedback by e-mail or a patient portal</li> <li>• A conference is a good idea for paying more attention to head and neck cancer</li> </ul>	<p>for more background information or explanation of the investigator</p> <ul style="list-style-type: none"> <li>• Organise a committee to monitor the content and format of the feedback report</li> <li>• Take case mix into account</li> <li>• Give feedback on the quality of data</li> <li>• Use specific themes each year when data will be compared on a national level</li> <li>• National feedback in the form of a conference is a useful idea; however, feedback in your own organisation will be useful as well</li> </ul>	<ul style="list-style-type: none"> <li>• National feedback in the form of a conference is a useful idea; however, it is better to discuss feedback in your own hospital first</li> </ul>	
Transparency	<p>General:</p> <ul style="list-style-type: none"> <li>+ Transparent for patients</li> <li>- Be careful that feedback is not interpreted carelessly</li> <li>- Be aware that results can change in a short time span</li> </ul> <p>Method:</p> <ul style="list-style-type: none"> <li>• Ask permission of the patient to receive their own results or the results of the general population</li> <li>• Make sure that you can trust the data: if a doctor gathers the data they could be less reliable</li> </ul>	<p>General:</p> <ul style="list-style-type: none"> <li>+ The only way to improve is to make data public/transparent</li> <li>+ To feel a sense of responsibility towards the population</li> <li>- Be careful with transparency; it is about vulnerable data</li> </ul> <p>Method:</p> <ul style="list-style-type: none"> <li>• Set up a committee to decide on issues related to transparency</li> <li>• Be critical in what a patient is able to understand</li> <li>• Make sure the specific hospital cannot be derived from the data presented</li> <li>• Only give feedback using scores of all hospitals when data will be presented anonymously</li> <li>• Investigate whether there are specific conditions to make the data public.</li> <li>• Make sure data are correct</li> </ul>	<p>General:</p> <ul style="list-style-type: none"> <li>+ Being transparent is good</li> <li>+ The only way to improve is to make data public/transparent</li> <li>- You cannot influence the indicators</li> </ul> <p>Method:</p> <ul style="list-style-type: none"> <li>• No anonymous feedback, only in the start-up phase</li> <li>• Be critical in what a patient can understand</li> <li>• Make sure that professionals are able to influence the indicators</li> </ul>	<p>General:</p> <ul style="list-style-type: none"> <li>+ To feel a sense of responsibility towards the population</li> <li>+ Visualise in order to improve healthcare</li> </ul> <p>Method:</p> <ul style="list-style-type: none"> <li>➤ Visualise as transparently as possible what type of care is delivered</li> </ul>

\* There is no information available on how the health insurer prefers to receive feedback since they prefer to receive raw data to develop their own figures.



**Table 6.** Preferences on the various figures.

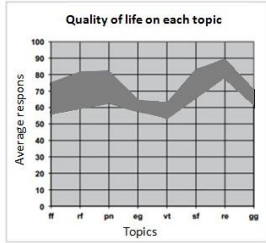
Figures	General perspective	Patient	Medical specialist	Allied health professional
<p><b>Kaplan Meier graph</b></p> 	<ul style="list-style-type: none"> <li>+ Gives a clear overview</li> <li>+ A classical way of presenting data, often used in science</li> <li>+ A good way of presenting, mainly for outcome indicators</li> <li>+ Most useful when there are big differences</li> <li>- Might be difficult for patients (and for some professionals too) to interpret</li> </ul>	<ul style="list-style-type: none"> <li>- For outcome indicators: too difficult to understand</li> </ul>	<ul style="list-style-type: none"> <li>+ For outcome indicators: gives a clear overview, seen as the classical way to present outcomes</li> <li>➤ Preference for this figure and a bar graph to present outcome indicators</li> <li>➤</li> </ul>	<ul style="list-style-type: none"> <li>- For outcome indicators: too difficult to read</li> </ul>
<p><b>Box plot</b></p> 	<ul style="list-style-type: none"> <li>- Gives a clear overview at a glance</li> <li>- A clear overview of how your hospital scores compared with the rest</li> <li>- Difficult to read for patients, and for some professionals as well</li> </ul>	<ul style="list-style-type: none"> <li>- For outcome indicators and process indicators: too difficult to understand</li> </ul>	<ul style="list-style-type: none"> <li>- For outcome indicators and process indicators: gives a clear overview at a glance</li> </ul>	<ul style="list-style-type: none"> <li>+/- For outcome indicators: for some people it could give a very clear overview, for others it is difficult to read</li> <li>- For process indicators: gives a less clear overview and is more difficult to interpret</li> <li>-</li> </ul>
<p><b>Point diagram</b></p> 	<ul style="list-style-type: none"> <li>- Does not give a clear overview whether all information is added into the same figure;</li> <li>+ Visualise all the information you want</li> </ul>		<ul style="list-style-type: none"> <li>- For outcome indicators: gives an unclear overview</li> </ul>	<ul style="list-style-type: none"> <li>+ For outcome indicators: gives an unclear overview</li> <li>+</li> </ul>

Figures	General perspective	Patient	Medical specialist	Allied health professional
<p><b>Bar graph</b></p> <p><b>A.</b></p> <p><b>B.</b></p> <p>Indicator percentage</p>	<ul style="list-style-type: none"> <li>- For a clear presentation of data</li> <li>- For patients, the bar graph is visually attractive and more clear to see compared with a pie chart, especially for elderly people</li> <li>+/- Can be used for the first overview, but afterwards you would prefer more detail</li> <li>+/- Insightful, although it might be difficult to read if more categories are used in one chart</li> <li>- Can become a very muddled and unclear figure</li> </ul>	<ul style="list-style-type: none"> <li>+ For outcome indicators (A): gives a clear overview</li> <li>+ For PROs and PREs: gives a more clear overview</li> <li>- For process indicators (B): too difficult to understand</li> <li>➤ Preferences for this figure and a pie chart to present PROs and PREs</li> </ul>	<ul style="list-style-type: none"> <li>- For process indicators (B): insightful</li> <li>- For PROs and PREs: is easier to read compared with a pie chart</li> <li>+/- For outcome indicators (A): can be difficult to read when several categories are used in the outcome indicators</li> <li>➤ Preferences for this figure to present outcome indicators and process indicators. A Kaplan–Meier graph is also preferred for outcomes</li> </ul>	<ul style="list-style-type: none"> <li>- For process indicators (B): gives a clear overview</li> <li>+/- For outcome indicators (A): can be difficult to read when several categories are used</li> <li>➤ Preferences for this figure to present outcome indicators and process indicators</li> <li>➤ Not a specific preference for a pie chart or a bar graph to present PROs and PREs</li> </ul>
<p><b>Pie chart</b></p> <p>Attention for pain in the treatment phase?</p>	<ul style="list-style-type: none"> <li>• Gives a clear overview, especially when there are big differences</li> <li>• Mainly for younger patients</li> </ul>	<ul style="list-style-type: none"> <li>• For PROs and PREs: gives a more clear overview</li> <li>➤ Preferences for this figure and a bar graph to present PROs and PREs</li> </ul>	<ul style="list-style-type: none"> <li>• For PROs and PREs: gives a clear overview</li> <li>➤ Slight preferences for this figure to present PROs and PREs compared with a bar chart</li> </ul>	<ul style="list-style-type: none"> <li>• For PROs and PREs: gives a more clear overview and is easier to read</li> <li>➤ Not a specific preference for a pie chart or a bar graph to present PROs and PREs</li> </ul>
<p><b>Funnel plot</b></p>	<ul style="list-style-type: none"> <li>+/- Gives a good overview but also contains a lot of information</li> <li>- Can be a complicated and unclear figure</li> </ul>	<ul style="list-style-type: none"> <li>- For process indicators: too difficult to understand</li> </ul>	<ul style="list-style-type: none"> <li>- For process indicators: gives a clear overview</li> <li>- Difficult to read at a glance</li> </ul>	<ul style="list-style-type: none"> <li>- For process indicators: gives a less clear overview and is more difficult to interpret</li> </ul>

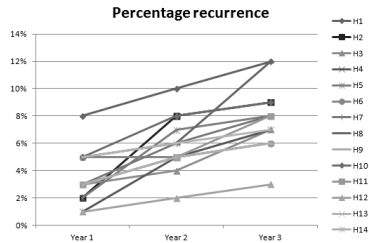


**Figures**

**Area graph**



**Line graph**



**General perspective**

- + Advantage is that all information is in one figure
- Not clear; the figure will probably be easier to understand with an explanation
- Difficult figure to understand directly
- Difficult for a patient to read; they never see this figure in daily life

**Patient**

- For PROs and PREs: too difficult to understand

**Medical specialist**

- +/- For PROs and PREs: more clear when a explanation is given, although it remains difficult as well: patients have probably never seen area graphs before

**Allied health professional**

- +/- For PROs and PREs: more clear when an explanation is given, at a glance it is a difficult figure to understand

- + Both insightful and unclear

- +/- For outcome indicators: it gives a lot of information but it is also confusing

- +/- For outcome indicators: it gives a large amount of information but it is also confusing

## DISCUSSION

This exploratory study investigated the preferences of receiving feedback on outcome, process and structure indicators in the DHNA from four different stakeholder perspectives: patients, medical specialists, allied health professionals including nurses, and health insurers. It shows that stakeholders agree that use of feedback can improve healthcare by creating awareness, by enabling reflection on oneself and colleagues, by benchmarking to others and by engaging quality of care discussions between parties involved. Patients prefer to receive feedback on quality indicators that match their healthcare pathway, whereas medical specialists and health insurers are interested mainly in outcome indicators. Furthermore, all stakeholders prefer a bar graph for feedback on most health outcomes and professional practice. In addition, patients prefer a pie chart for PRO experiences, while a Kaplan–Meier graph is preferred specifically for survival curves by medical specialists. Feedback should be simple and intended to give an overview firstly. Moreover, it should be sent by e-mail with a frequency of 1–4 times a year.

Other literature is focussed mainly on preferences of patients or clinicians, but this study includes preferences of four different stakeholders<sup>22,37,38</sup>. It is also directed towards different types of indicators, namely process, structure and outcome indicators. Furthermore, it gives a clear overview of why, what and how patients, professionals and health insurers prefer to receive feedback.

Our study confirms that feedback is a method for reflection and for creating awareness, resulting in a change in behaviour<sup>1,22</sup>. Also, patients and professionals mention that knowing the hospital's scores on PROs and PREs can improve the quality of care. Greenhalgh showed already that the use of PROs in clinical practice is valuable in improving the discussion and detection of health-related quality of life problems<sup>39</sup>.

In line with previous literature and irrespective of the stakeholder, simple formats, such as bar graphs, were generally preferred to more complex graphical information<sup>20,40,41</sup>. Regarding PROs and PREs, our study shows that both a pie chart and a bar graph are preferred by patients. Professionals have a slight preference for a pie chart over a bar graph. Hildon et al. described that patients often prefer a bar graph, since it is a clearer graph visually<sup>42</sup>. Moreover, patients' preferences for a bar graph are in line with Kuijpers et al<sup>20</sup>. In addition, Hildon et al. described that a funnel plot was difficult to read for patients, which our study confirms as well<sup>42</sup>.

Although our patient population prefers a figure over plain text, they would also prefer an explanation to go with the figure. This is in line with Brundage et al., who stated that patients did not wish to receive HRQL information out of context or without explanation<sup>40</sup>, and also with Tufte, who gave an overview of the characteristics that a well-readable graph should have<sup>43</sup>.

## **Strengths and limitations**

The fact that only three health insurers participated in the study could be considered a limitation. This is probably too small to reach saturation (the point at which no new information was mentioned in the interviews)<sup>34</sup>. However, the health insurers shared the same thoughts on the topics discussed. Bias may have occurred when selecting the patients, since it is possible that patients with a higher social status and adequate communication skills were selected by each hospital, resulting in a less representative patient population. HNC is associated with poor socioeconomic circumstances<sup>44</sup>. In the interviews, it became clear that it was difficult for patients to understand the feedback regarding health outcomes, such as recurrence rates. Therefore, the interviews with patients were directed mainly towards the use of feedback on PROs and PREs, when we spoke about 'health outcomes'. Questions for the health insurers merely focused on the goal of feedback, because the insurers mentioned that they prefer raw data instead of receiving a complete report.

Lastly, there might be an overvalue of positive preferences for feedback. This study shows that all stakeholders are positive about receiving feedback on professional practice and healthcare outcomes. However, if this view would manifest itself in action, you would expect that the literature on implementation of audit and feedback would show much larger and more consistent effect sizes. This is similar to the situation in which adherence to clinical guidelines is still low and clinicians often overstate their adherence to the guidelines<sup>45-47</sup>. Knowing how stakeholders prefer to receive audit and feedback does not assure that they will actually respond to it. Therefore, it is necessary to test the response in practice.

## **Conclusion**

This exploratory study shows that preferences for receiving feedback between patients, professionals and health insurers differ regarding content but not regarding layout. Therefore, reports tailored to these preferences are recommended. Using this information, the effect of audit and feedback can be improved by adapting the feedback format and contents to preferences of stakeholders. As a result, this could potentially improve quality of care. A next step is to test in practice to what extent professionals actually respond if audit and feedback suit their preferences.

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## CHAPTER 7

### General discussion



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## **THE DUTCH HEAD AND NECK AUDIT: THE FIRST STEPS**

The treatment of Head and Neck Cancer (HNC) is an excellent example of low volume, highly complex, multidisciplinary integrated care. HNCs are heterogeneous (both biologically and in clinical behaviour) fast-growing tumours in an anatomically and functionally complex area, with multiple invasive treatment opportunities. Several health professionals, such as medical specialists (head and neck surgeons with expertise in Ear Nose & Throat (ENT) and Oral Maxillofacial (OMF) surgery, radiotherapists, medical oncologists, pathologists and radiologists) and allied health professionals (dietitians, speech pathologists, physical therapists, oral hygienists and oncology nurses) are involved in delivering high quality care to individual patients. To increase the quality of care, coordination is crucial<sup>1</sup>, resulting in less fragmentation and unnecessary replication.

To monitor and effectively improve high quality integrated care, a clinical audit can be set up. A clinical audit is defined as "a quality improvement process that seeks to improve patient care and outcomes through systematic review of care against explicit criteria and the implementation of change"<sup>2</sup>. The Dutch Head and Neck Audit (DHNA) was set up in 2014 to monitor the quality of integrated HNC care (with quality indicators as a basis), to benchmark and to find areas for improvement. Quality indicators were developed from three different perspectives: medical specialists, allied health professionals and patients. Following one year of inventory and building an online quality registration system<sup>3,4</sup>, the first data were collected to fill the indicators in 2015-2016<sup>5</sup>. The preferences of health professionals and patients in receiving feedback on results were investigated as well<sup>6</sup>. In this chapter, the main findings of the project from the perspective of the current status of HNC care in the Netherlands will be addressed. Also, the methodological considerations and the implications for clinical practice, future research and policymaking will be described.

## **CHARACTERISTICS OF THE DHNA**

### **One of a kind**

The DHNA is the first quality of healthcare registration system in the Netherlands involving both medical specialists and allied health professionals, with all indicators agreed upon by patients. In other words, the DHNA is a truly multidisciplinary registration. Most quality registrations are currently monodisciplinary or only involve process indicators from the medical specialists' perspective<sup>7</sup>. A monodisciplinary audit focuses on process performance and patient outcomes from the perspective of one discipline with the aim of improving quality of care. However, multidisciplinary care is nowadays more common, as several disciplines contribute to patient outcomes. A good example of this is the 'swallow function' after a curative treatment for an HNC: this can be influenced by both medical treatment and supportive care of the speech therapist or dietician<sup>8</sup>. Quality is often a result of both.

The DHNA is also one of the first HNC quality registrations on an international level. Other countries already have databases with the aim of improving quality of care and patient outcomes, for example, the Head And Neck Audit (HANA)<sup>9</sup> in the UK, or the Danish Head and Neck Cancer database (DAHANCA)<sup>10</sup>. These databases, however, were built from an epidemiological perspective for clinical trials and did not use predefined evidence-based quality indicators from the start. An epidemiological database is not primarily intended for quality registration from the perspective of process indicators, PROs and PREs<sup>11</sup>.

### **Selection method based on both process and outcome indicators**

The basic assumption for the quality indicator development procedure used for the DHNA was that outcome indicators formed the basis of process and structural indicators. The DHNA outcome indicators followed the three-tiered hierarchy for value-based healthcare, as developed by Porter<sup>12</sup>. The first level, e.g. survival, is generally the most important, and lower-tier outcomes, e.g. sustainability of health, follow the success of higher tiers. We therefore followed the current trend to focus on outcomes<sup>13</sup>, such as disease-specific mortality and survival or PROs. Previous research shows that the preference for an outcome indicator comes from the fact that it is a measure of something that is important in its own right, whereas the process indicator is only of value when it is assumed to have a link to outcomes<sup>14</sup>.

There are three reasons not to focus solely on outcome indicators. Firstly, process indicators are more sensitive in measuring differences in quality of care<sup>14</sup>. Secondly, a process indicator is easier to interpret, whereas an outcome indicator, for example mortality, is a rather more indirect measure<sup>14</sup>. Thirdly, by only measuring outcome performance, there is no information on how to begin addressing problems.

When a hospital discovers poor performance for one particular outcome, the first step is to dissect the outcome into its different components, and to ensure adherence to all best practice recommendations at process level<sup>13</sup>. For these reasons, outcome indicators seem to be a measure of quality of care to a lesser extent<sup>15</sup> and some researchers push the pendulum back towards process measures<sup>13</sup>. This sets the development of an extensive set that contains both process and outcome indicators, as necessary tools to improve quality of care.

Incorporating the indicators on outcome, process and structure, a broad view is presented on patient-related outcomes, patient-related processes and hospital-related processes. However, the link between process and outcome indicators is often unclear. This is mainly since many data and sufficient follow-up years are necessary to analyze this association. With the DHNA, the link between process and outcome indicators can be analyzed when more data are available in the future. Furthermore, incorporating the indicators on outcome, process and structure might easily result in an extensive set of quality indicators. This is especially the case when both medical specialists and allied health professionals provide indicators.

## **Privacy and juridical challenges for collecting patient data**

To analyze the data on a national level in order to measure the quality of healthcare, an online registration system was developed. The PROs and PREs are requested via online patient questionnaires, the remaining data are recorded by healthcare providers themselves in the DHNA. All collected data are stored in a database. This database forms the basis for the automatic feedback system. To ensure that data will be saved correctly and that data will be analyzed according to current rights and privacy regulations, it was necessary to set up contracts between the HNC centers and the data processors. However, hospitals and their HNC centers appeared to have their own interpretation of legal regulations. Therefore, setting up contracts to exchange data from the hospital to the data processor was difficult. The contract was prepared with the utmost care, taking aspects as exchange of encrypted data and ownership into account. However, the lawyers of several hospitals demanded changes in the contract. Apart from this being a time-consuming process, lawyers could not reach consensus. This strikes the need for a uniform regulation about privacy aspects.

## **CURRENT QUALITY OF HEAD AND NECK CANCER CARE IN THE NETHERLANDS**

Using the perspectives of both medical specialists and allied health professionals, evidence-based quality indicators and case mix variables were developed which were agreed upon by patients<sup>3</sup>. The final set of indicators consisted of five outcome indicators (survival, recurrence, complications, patient reported outcomes (PROs) and patient reported experiences (PREs)), 13 and 18 process indicators from the medical specialist perspective and the allied health professional perspective respectively, while three structure indicators from the allied health professional perspective were developed within the DHNA. From the patients' perspective, a total of 34 relevant themes of needs and preferences were identified to obtain tools to make current integrated HNC care more patient-centered<sup>4</sup>. The results and usefulness of three indicators will be discussed in this paragraph. The first indicator discussed is survival, since this is one of the most important outcomes relevant for both patients and professionals. Hereafter time to treatment interval is discussed since patients noted that there is an urgent need to reduce waiting times in the hospital. Finally, the patient reported outcomes are discussed since these are increasingly used to measure quality of care and provide us with information about how the patient feels.

### **Survival**

Previous (European) studies showed that the survival of HNC patients in the Netherlands is relatively high<sup>16,17</sup>. Compared to other countries in Europe, the Netherlands is one of the best performers on survival. In a EURO CARE-5 population-based study for head and neck cancers diagnosed in the early 2000s for example, five-year survival for patients with laryngeal cancer is

68.9% in the Netherlands as compared to 58.9% in Europe. For patients with oral cancer the difference is similar, namely 56.1% in the Netherlands compared to 45.4% in Europe<sup>17</sup>. This shows that HNC care in the Netherlands is relatively superior with regard to survival, which could be indicative for quality of care. This might be due to the concentration and centralization of HNC care since 1984 under the umbrella of the Dutch Head Neck Society (DHNS)<sup>18</sup>. Monitoring of the quality of integrated HNC care using the DHNA provides opportunities to further explore the association between survival and quality of care.

### **Time to treatment interval**

In the Netherlands, all professional associations related to HNC care agreed that 80% of all new patients should receive their primary treatment within 30 calendar days from the first consultation at an HNC center. However, nationwide, only 48% of the patients start with their treatment within 30 calendar days, with a variation of 20-72% in different HNC centers<sup>5</sup>. A previous study in the Netherlands (2007) shows an average 'time to treatment interval' of 28 days with a variation of 5-95 days between diagnostic and radiotherapy planning scans<sup>19</sup>. So, results have not changed that much in ten years and further improvement is still possible. By visualizing 'time to treatment interval' using the DHNA, and providing active feedback to health professionals, this can be improved in the future.

### **Patient Reported Outcomes (PRO)**

The Netherlands is one of the countries that seem to be most advanced in implementing PROs, and it also appears to be leading in the way of inclusion of PROs in national registries<sup>20</sup>. Internationally, there is a policy shift towards value-based healthcare and health outcome evaluations, such as in the UK, USA, Sweden and the Netherlands. The first DHNA results concerning the PROs showed that function and symptoms differ between type of treatment, follow-up moments, age and tumour staging<sup>6</sup>. Results and methods used were comparable to other studies<sup>21,22</sup>. Many studies focus on differences in patient-reported outcomes and on what can be done by hospitals and health professionals to increase the effectiveness of using PROs<sup>23</sup>. However, a crucial step in value-based healthcare is the effectiveness of measuring PROs on patient outcomes such as survival. A good example of this is given by Basch et al., who recently stated that survival increases significantly in patients who monitored symptoms with PROs compared to patients who received standard care<sup>24</sup>. So far, this is studied to a lesser extent and will be one of the aims of the DHNA for the future.



## **CURRENT TOOLS FOR IMPROVING QUALITY OF HEALTHCARE**

### **Variation in delivered HNC care already visible**

Does this set really facilitate monitoring and improvement of the quality of healthcare? In general, an audit registration such as the DHNA needs a couple of years of data to provide stable results<sup>25</sup>. As the first data were collected in December 2014, it is too early yet to present results on all indicators. Preliminary results of the DHNA show that, even in a recently launched quality registration, with 2,400 new HNC patients included, variations in the delivery of current processes of care among HNC centers is already visible. Feedback on indicators in the DHNA is given via an automatic online system, which is only accessible by staff at individual HNC centers, who are able to view the score of other HNC centers anonymously along with the average score<sup>7,26</sup>. This system allows health professionals to easily compare the performance of their own HNC center with a nationwide benchmark, upon which they can start acting on their own results. For example, the first results of the quality registration showed a variation between hospitals on the indicator of delay from the first consult to finishing the diagnostics and to the start of the curative therapy. Subsequently, the first hospital site visits were planned to share practice experience towards decreasing lead-time or delay. Besides transparency within and between hospitals, the first results of the DHNA can also be shown to the public in the upcoming years, in other words: public transparency.

### **Results already visible for patients**

For most outcome indicators, such as recurrence rates and survival, it takes several years before stable and reliable data are complete enough to be interpreted. However, currently some results of the DHNA are already visible for patients, namely PROs and PREs. PROs and PREs are collected with questionnaires at several follow-up moments using an automatic online system. Currently, patients can directly see how their results differ from the last time. In addition, they can bring along the results to the medical consult and discuss their concerns or ask for possible solutions. In the future, the health professional can also check for outliers or relevant differences compared to a previous consult in his own electronic system, prior to the consult. Together with the patient, they can start acting on the results at an earlier stage, thus improving rehabilitation. Therefore, an automatic feedback loop toward the patient and the health professional and introducing the relevance of PROs in a medical consult can improve quality of care in small steps and earlier on, compared to quality improvements depending on aspects such as recurrence rates and survival.

### **Feedback**

Although positive effects of audit and feedback in general have been reported, e.g. decreased duration of hospital stay<sup>27</sup> and decreased mortality rates<sup>28</sup>, this method of improving quality of care has not been found to be consistently effective<sup>29-32</sup>. Previous research shows that the format

of feedback may significantly affect the interpretation of data<sup>33-35</sup>. The DHNA showed that tailored reports of feedback on professional practice and healthcare outcomes are recommended, since feedback preferences differ between patients, medical specialists, allied health professionals, and health insurers<sup>26</sup>. In general, the preferences for receiving feedback differ regarding content but not regarding lay-out. This knowledge gives us tools to improve the effects of audit and feedback by adapting the feedback format and contents to the preferences of stakeholders. In the start-up phase of the DHNA, the first feedback is given in a uniform lay-out. Now steps can be undertaken to individualize feedback.

## METHODOLOGICAL CONSIDERATIONS

### Challenges in developing indicators

Developing evidence-based indicators for the DHNA from the perspective of allied health professionals proved to be rather a challenge, as there are hardly any (inter)national guidelines that provide evidence-based recommendations for daily healthcare delivery<sup>3</sup>. The indicators were developed in collaboration with the Dutch national foundation for allied health professionals in this specialist sector – the *Paramedische Werkgroep Hoofdhalstumoren* (PWHHT). Panel members were instructed to discuss the potential indicators with the allied health professionals of their own discipline, in their own center, and in other Dutch HNC centers as well. For some disciplines, variation in delivery of care between the different centers became visible. Therefore, the development of indicators was more of a starting point for debate about how HNC care should be delivered. As a consequence, development of indicators from the allied health perspective took more time to reach agreement compared to medical indicators. Discussion remained for the indicators developed from the perspective of speech therapists. Therefore, new indicators were developed after one year. Overall, to develop evidence-based indicators, evidence-based guidelines or literature are important requirements. However, evidence-based guidelines are not always available for rare diseases. A well-performed consensus procedure is then necessary to develop useful indicators.

### Interpreting results

When interpreting quality indicator scores, it may be difficult to distinguish between a lack of documentation and actual insufficient adherence to guidelines. For example, if the indicator '*Presence of a case manager or nurse practitioner at the consultation to discuss the treatment plan*' does not have a positive score, it could mean that the case manager was not present, or that this was not documented, as such. In addition, to reliably benchmark the performance of one hospital compared to average national performance, it is crucial that all hospitals include all their patients. Otherwise, with only a proportion of patients, it is impossible to calculate a stable indicator, as 1) it is unknown which patients are missing, and 2) variations in patient numbers can

influence the adherence percentage. If this happens for outcome indicators, it might set both the hospital and the national performance at a disadvantage. Therefore, during the first year most registrations merely focus on developing indicators and quality registration; the second year on ensuring that all data will be collected; while in the third year the first results are anonymously presented.

## **FUTURE PERSPECTIVES**

By the end of 2016, the DHNA was able to include approximately one third of all new curatively treated patients from November 2014, with complete datasets onwards. This could be interpreted as a rather low input. However, one must take into account that this project, with indicators from the perspectives of medical specialists, allied health professionals, and patients, and from referral to follow-up, has prompted a lot of effort from individual therapists, ICT systems and work processes. A couple of wise lessons were learned from this project, and will be explained in this section.

### **Implications for clinical practice**

#### ***Increase support of health professionals***

Setting up a multidisciplinary quality registration is quite challenging and time-consuming. For a successful quality registration, it is important that it is set up for and through health professionals<sup>25</sup>. Considering examples seen in other countries, we know that a government-administered head and neck cancer registration has nearly failed, because the support of health professionals was missing (British HANA)<sup>13</sup>. With a 'saving' plan, many resources are spent on improving the support and inclusion of the registration. The DHNA is an example of a quality registration in which the health insurer was involved as a partner, next to the health professionals, when developing the quality registration. This is also called 'tripartite'. Besides health professionals, involving the hospital Board of Directors could be a large opportunity to improve care from a policy level. The importance of involving the Board of Directors is also seen by the Netherlands Federation of University Medical Centres (NFU). The DHNA participates in one of its first pilots in the project '*Sturen op kwaliteit*'<sup>36</sup>.

#### ***Registering at the source***

The website of the National Institute for Public Health and Environment – the '*Rijksinstituut voor Volksgezondheid en Milieu*' (RIVM), in the Netherlands states that there are currently 181 active registrations, while annual costs for quality registrations are estimated at 80 million euros<sup>37,38</sup>. These costs are currently spent on registrations and not directly on the patient. One way to decrease the registration burden and the associated costs is to reduce the number of

registrations and to make the quality registrations as comprehensive as possible. Another method to decrease the registration burden is to automate data subtraction from hospital electronic patient records. To build an IT-reliable automatic subtraction system is, of course, initially expensive, but not in the long run. Furthermore, Govaerts et al. show that improved outcomes due to auditing can also reduce costs<sup>39</sup>.

The first steps to lower the registration burden for health professionals that register in the DHNA have already been taken by engaging the Netherlands Cancer Registry (NCR) in a close cooperation. The NCR has 30 years' experience in data registration on incidence and survival. However, these employees are paid from another source, namely the government. Furthermore, the DHNA participated in two projects of 'Registering at the source'. This program has been developed in cooperation with the NFU and aims to automatically subtract variables for the DHNA from the patient electronic record. In a couple of years the registration burden of the DHNA can be significantly decreased.

### ***Transparency***

In general, some health professionals might have a less positive attitude towards public transparency, because they fear that they may be judged and that (social) media might misinterpret the indicators. However, besides public transparency, the key to achieving improvement collaboratively is to share results within a hospital or between hospitals. Therefore, it is crucial to present the results in such a way that they support collaborative improvement, but also represent a safe platform to share results. Moreover, the method of communication about this kind of non-public transparency is important and should not be neglected.

## **Implications for future research**

### ***Improve quality of care***

Previously, oncologic care was only evaluated by a few standards from the Dutch Federation of Oncologic Specialties (SONCOS)<sup>40</sup> and the Healthcare Inspectorate as an independent supervisor in Dutch healthcare (IGZ)<sup>41</sup>. These data were collected for accountability and were not used to improve quality of care. The data from the DHNA provides the first opportunity to visualize differences in outcomes and practice performance at a national level. With this information, more research can be directed towards variation in current practice between different centers. Best practices can be framed, and ultimately, data can be used to improve quality of care. In addition, from the first results of the DHNA, we know that variation between centers is present, and that four determinants on patient and hospital level influenced the indicator scores<sup>5</sup>. When more data are available, research can be directed towards all indicators to explore the variance and possible patient and hospital determinants.

### ***Patient reported outcomes and experiences***

The DHNA shows that patients with multimodality treatments experience a less well-organized healthcare process, suffer from lower functional scores and more symptoms compared to patients with a monomodality treatment<sup>6</sup>. In the future, more data should be collected to obtain more insight into long-term quality of life and patients' experiences. Apart from carrying out research on the outcomes, studies towards the effectiveness of measuring PROs should be undertaken to increase patient outcomes such as survival.

### ***Evaluation of quality indicators of the DHNA***

The first quality indicators for the DHNA were developed in the start-up phase of the quality registration. After three years, more data will be obtained, enabling more reliable feedback on a national level and a hospital level. This gives us tools to evaluate the indicators. However, before making a decision on the indicator, it is important to evaluate why an indicator is performing well or poorly. For example, if care is delivered, but not registered as such, it is crucial to improve the registration processes in the patient records instead of continuing the quality registration in the same way.

### ***Go global***

Besides comparing quality of care between different HNC centers in the Netherlands, it would be interesting to compare the quality of HNC care to other countries in Europe<sup>17</sup>. In addition, international research projects can be initiated to investigate international variations in performance of HNC care, to learn from each other and to improve current HNC care. An already existing consortium is the 'International Consortium for Health Outcomes Measurement' (ICHOM), which measures international patient outcomes. At this moment, no international HNC indicator set exists under the umbrella of ICHOM. The DHNS with its DHNA can provide input for the development and its implementation.

## **Implications for policy making**

### ***Development of good quality indicators for future registrations***

Besides a clear definition of the concept to be measured and the target population, the origin of the indicator is important<sup>42</sup>. It was difficult to develop evidence-based indicators from the perspective of allied health professionals in the DHNA, mainly because there were no national guidelines<sup>3</sup>. Campbell et al. have previously described that evidence-based quality indicators form the foundation for a good quality registration, preferably developed by an evidence-based method<sup>3,43,44</sup>. However, the results from the quality registration could start a dialogue between disciplines working in different HNC centers. It could provide the first tools to discuss where and why HNC care is delivered differently in order to reach consensus about best practice. Quality

indicators themselves can therefore be the evidence to improve clinical practice and, therefore, reframe national guidelines.

### ***Monodisciplinary versus multidisciplinary***

A monodisciplinary quality registration will depend to a lesser extent on the support of different health professionals, compared with a multidisciplinary quality registration. This is most notably the case when the multidisciplinary registration involves both medical specialists and allied health professionals. This will make the implementation of the quality registration more complex. However, with a multidisciplinary registration, the quality of care provided by all disciplines can be measured. In that case, a multidisciplinary healthcare process benefits from a multidisciplinary quality registration. Therefore, a clear decision on the aim should be made, while weighing the advantages and disadvantages of a multidisciplinary registration and a monodisciplinary registration for each (oncologic) disease.

### ***Privacy and juridical restrictions***

This project was not the first to encounter privacy and juridical problems, and will also not be the last. We tried to expand the discussion to a national level with various relevant parties. Unfortunately, the importance of making these processes less bureaucratic was not shared by national organizations. However, such problems are encountered on a local level, yet require a solution on a national level, while hopefully a uniform regulation on a national level will follow in the future. It is crucial that research projects continue to indicate the problems to make directors more aware of the problem.

## **FINAL CONCLUSION**

The DHNA is the first quality of healthcare registration system in the Netherlands that involves both medical specialists, allied health professionals and patients. In addition, it is also one of the first HNC quality registrations on an international level. Therefore, this project shows that the development of a multidisciplinary quality registration for patients with HNC from three different perspectives, namely patients, medical specialists, and allied health professionals, is feasible. Outcome indicators formed the basis of process and structural indicators, while all indicators are evidence-based. A key element to implement an efficient HNC registration was to keep the health professionals involved.

We know that current HNC care in the Netherlands is well organized and it seems effective with regard to survival results<sup>16,17</sup>. However, preliminary results from the DHNA show that care can be improved and that it varies among different hospitals at certain points. In the future, more data is needed to better explain the variation and possible patient and hospital determinants, to obtain more insight into long-term quality of life and patients' experiences, and to define the relation between PROs and PREs and patient outcomes such as survival. Hereafter, results can be shared

within a hospital or between hospitals to support collaborative improvement. When hospitals give permission, data can become transparent to the public as well. In addition, it would be interesting to compare the quality of HNC care with other countries in Europe.

Efforts should be made on a national level to solve privacy and juridical restrictions for quality registrations. In addition, the registration load should be decreased with the use of IT-reliable automatic subtraction systems. With more data and a reduction of the registration load, the focus of the DHNA will move from registration of data to improving quality of HNC care. So far, the first steps to improve quality of care have already been taken. Examples of existing quality improvement steps are the visibility of indicator scores with corresponding benchmarks in a hospital specific online feedback report, hospital site visits to share practice experiences toward decreasing time to treatment interval, and the visibility of patients' own results regarding PROs and PREs. In the upcoming years, more such steps will be taken to improve quality of healthcare for patients with HNC in the Netherlands.

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## CHAPTER 8

### Main findings, summary and samenvatting



## **MAIN FINDINGS**

### **Development of quality indicators for integrated head and neck care**

- 1) A comprehensive set of evidence-based quality indicators from three different perspectives (medical specialists, allied health professionals and patients) over the entire HNC pathway was developed (Chapters 2 & 3).
- 2) The perspective of the patient, the medical specialist and the allied health professional are essential in each phase of care: the diagnostic, treatment and follow-up phases (Chapter 2).
- 3) Similar outcome indicators were developed from the perspective of medical specialists, allied health professionals and patients, focusing on survival, recurrence and complication rate, as well as patient reported outcomes (PROs) and patient reported experiences (PREs) (Chapter 2).
- 4) Process indicators from the perspective of medical specialists focused more on the diagnostic phase and on organizational aspects, such as high quality multidisciplinary team meetings and diagnostic and therapeutic delay. Process indicators from the perspective of allied health professionals focused more on the functional and psychosocial status of the patient before, during and after treatment (Chapter 2).
- 5) Patients' needs and preferences emerging from the study concerned a) the diagnostic, treatment, and surveillance phases, and were related to b) both medical specialists and allied health professionals. Patients needed a more 'Personalized diagnostic phase', and 'Adequate involvement of the general practitioner in the aftercare for an optimal transfer'. They also needed 'Personalized involvement of allied health professionals for physical support', 'Involvement of the oncology nurse for time saving during the consultation with the doctor and more personal contact', and 'Doctor-patient relationship relies on integrity and mutual respect' (Chapter 3).

### **First results of the quality registration**

- 1) Despite the fact that registration has recently started, differences in the care provided were found on the basis of the jointly appointed indicators; the indicator for the availability of a treatment plan had the highest score and variation between hospitals was small, while the indicator for a case manager or nurse practitioner being present at the consultation to discuss the treatment plan had the lowest score and a high variation (Chapter 4).
- 2) Three determinants at patient level and one determinant at hospital level influenced the scores of different indicators (tumour stage, performance status, tumour site and number of new patients per year) (Chapter 4).

- 3) Patients with multimodality treatments (combination of treatments) tended to experience a lesser well-organized healthcare process, while also having worse functional scores and more symptoms compared to patients with a monomodality treatment (Chapter 5).

### **Audit and feedback**

- 1) According to the different stakeholders (patients, medical specialists, allied health professionals and insurance companies) regular feedback can improve healthcare through creating awareness, benchmarking to other hospitals, engaging quality of care discussions between parties involved, and by providing focus for actions to improve the quality of care (Chapter 6).
- 2) Feedback preferences differed between stakeholders on the frequency and indicator types, which makes tailored reports preferable (Chapter 6).
- 3) Medical specialists preferred to receive feedback on process indicators (one to four times a year) more often compared to outcome indicators (one to two times a year) (Chapter 6).
- 4) Allied health professionals preferred to receive more feedback on outcome indicators rather than on process indicators. Furthermore, allied health professionals preferred to receive the indicators of their own discipline first, followed by the remaining indicators, whereas patients preferred indicators that match the care received (Chapter 6).



## **Summary**

## SUMMARY

In **chapter 1** general information about Head and Neck Cancer (HNC) is provided, explaining more about the incidence, survival, symptoms, risk factors, treatment, and the need for standardization of care. In addition, a quality registration to measure quality of care using quality indicators is explained. Finally, the main objectives and outline of the thesis are described.

### **Development of quality indicators for integrated head and neck care**

Oncological care is very complex, and delivery of integrated care with optimal alignment and collaboration of several disciplines is crucial. A dashboard of valid and reliable quality indicators is indispensable to monitor and effectively improve high quality integrated oncological care. **Chapter 2** describes the development of quality indicators to measure quality of integrated oncological care, specifically for head and neck cancer (HNC) patients. For this purpose, the RAND-modified Delphi method was used to decide on the outcome, process, and structure quality indicators from three different perspectives: patients, medical specialists and allied health professionals involved in HNC care. In the final set, outcome indicators were assigned to healthcare status, tumour recurrence, complications, quality of life, and patient experiences. The process indicators focused on the (allied health) care aspects during the diagnostic, treatment, and follow-up phases; for example on waiting times, multidisciplinary team meetings, and screening for malnutrition. Developed case mix factors focused on patient characteristics such as gender, age and tumour stage. This set can be used to build other oncological quality dashboards for integrated care.

**Chapter 3** explores the needs and preferences of patients with head and neck cancer (HNC), to adapt current integrated care to a more patient-centered integrated care. Semi-structured interviews were held with 14 current and former patients and chairmen of two Dutch HNC patient associations to identify all possible needs and preferences. In addition, needs and preferences were categorized using the eight dimension Picker model of patient-centered care. A total of 34 themes of needs and preferences were identified and categorized into the eight Picker dimensions. Themes that often emerged were: personalization of healthcare regarding patient values, clear insight into the healthcare process at an organizational level, use of personalized communication, education and information that meets patients' requirements, adequate involvement of allied health professionals for physical support, more attention to the impact of HNC and its treatment, adequate support from family and friends, adequate general practitioner involvement during aftercare, and waiting time reduction. Monitoring the identified themes in integrated HNC care will enable us to respond better to the needs and preferences of patients, while patient-centered care in oncological care can be enhanced.

## First results of the quality registration

**Chapter 4** describes the assessment of current head and neck cancer care using quality indicators, particularly the variation among Dutch hospitals, and the influence of patient and hospital characteristics. Data for calculating quality indicator scores were collected by means of self-registration of 1,667 curatively treated patients in eight hospitals. A multilevel analysis was used to explain the variation between Dutch hospitals and to analyze the influence of patient and hospital characteristics. The quality of current care varied between the different hospitals: the indicator for the availability of a treatment plan had the highest score and variation between hospitals was small, while the indicator for a case manager or nurse practitioner being present at the consultation to discuss the treatment plan had the lowest score and a high variation. At patient level, higher quality indicator scores were associated with lower performance status, an advanced tumour stage, and the presence of tumours in the oral cavity and oropharynx in three indicators, namely: the indicator for involvement of a dental team before radiotherapy, for the start of the first treatment within 30 days, for finishing diagnostics within 21 calendar days, and for malnutrition screening. At hospital level, higher quality indicator scores were associated with more curatively treated patients (volume) in three indicators, namely: the indicator for registering whether the patient was treated according to the protocol, for referral to the hospital within 7 calendar days, and for finishing diagnostics within 21 calendar days. We conclude that although the quality registration had only recently been launched, it already visualizes hospital variation in current care. Four determinants are of influence in this respect: tumour stage, performance status, tumour site, and number of new patients per year. However, more data are needed to assure stable results for use in quality improvement.

Monitoring how patients feel and what they experience during the integrated care process gives health professionals tools to improve their care. In **chapter 5** we obtained more specific improvement aspects for different treatment methods by measuring Patient Reported Outcomes (PROs) and Patient Reported Experiences (PREs) in integrated HNC care for both patients with monomodality and multimodality treatment. Validated PRO Measures (PROMs), yielded global health status, functional scores, and symptom scores (EORTC-C30 & H&N35) were completed at baseline and 3, 6 and 12 months after the last treatment. The PRE Measure (PREM) (Dutch CAHPS), including domains such as organization and cooperation, was completed at 12 months after diagnosis. Descriptive analyses were used to assess trends in PROs over time and the difference between monomodality and multimodality treatment in PROs and PREs. This study showed that patients with multimodality treatment tend to experience a lesser well-organized healthcare process, have worse functional scores and more symptoms compared to patients with a monomodality treatment. In addition, patients with radiotherapy treatment alone suffered from less functional scores and more symptoms compared to patients with surgery alone. Given the higher incidence of symptoms and loss of functioning in patients after multimodality



treatment in particular, the follow-up phase should be more personalized and directed to rehabilitation for restoring function and decreasing symptoms.

## **Audit and feedback**

**Chapter 6** explores the (differences in) preferences of receiving feedback between stakeholders in the DHNA. Therefore, semi-structured interviews were held with a total of 37 patients, medical specialists, allied health professionals, and health insurers. All stakeholders mentioned that feedback can improve healthcare by creating awareness, enabling self-reflection and reflection on peers or colleagues, and by benchmarking to others. Patients preferred feedback on the actual professional practice that matches the healthcare received, whereas medical specialists and health insurers were mainly interested in healthcare outcomes. All stakeholders largely preferred a bar graph. Patients preferred a pie chart for patient reported outcomes (PROs) and experiences (PREs), while Kaplan Meier survival curves were preferred by medical specialists. Providing feedback should be simple with firstly an overview, and 1-4 times a year sent by e-mail. Finally, patients and health professionals were cautious with regard to transparency of audit data. In conclusion, this exploratory study shows how feedback preferences differ between stakeholders.

Finally, in **chapter 7** the main findings of this thesis are discussed in the light of recent literature, and implications for future research, clinical practice and policy making are outlined.

## **Samenvatting**

## SAMENVATTING

In **hoofdstuk 1** wordt algemene informatie gegeven over hoofd-halstumoren (HHT), met name over het aantal nieuwe patiënten, overleving, symptomen, risicofactoren, behandeling en de behoefte aan standaardisering van de zorg. Daarnaast wordt het begrip kwaliteitsregistratie toegelicht, evenals het belang van kwaliteitsindicatoren voor zo'n registratie en het meten van de kwaliteit van zorg. Tenslotte worden de hoofddoelstellingen en de inhoud van het proefschrift beschreven.

### **Ontwikkeling van kwaliteitsindicatoren voor geïntegreerde hoofd-hals oncologische zorg**

Het leveren van geïntegreerde zorg met optimale samenwerking tussen verschillende disciplines is van cruciaal belang. Een kwaliteitsregistratie met valide en betrouwbare kwaliteitsindicatoren is onmisbaar om de geïntegreerde oncologische zorg te monitoren en effectief te verbeteren. **Hoofdstuk 2** beschrijft de selectie van kwaliteitsindicatoren om de kwaliteit van geïntegreerde oncologische zorg te meten voor patiënten met hoofd-halstumoren: de Dutch Head and Neck Audit (DHNA). De RAND-gemodificeerde Delphi methode is gebruikt om kwaliteitsindicatoren op uitkomst-, proces- en structuurniveau te selecteren vanuit drie verschillende perspectieven: patiënten, medische specialisten en paramedici betrokken bij HHT-zorg. In de uiteindelijke set zijn uitkomstindicatoren geselecteerd op het gebied van overleving, recidief, complicaties, kwaliteit van leven en patiëntervaringen. De geselecteerde procesindicatoren zijn gericht op handelingen van medisch specialisten en paramedici in de diagnostische, behandelings- en nazorgfasen, bijvoorbeeld wachttijden, kwaliteit van het multidisciplinair overleg en screening voor ondervoeding. Patiënteigenschappen die vanuit de verschillende perspectieven ook van belang worden geacht om mee te nemen in de kwaliteitsregistratie zijn geslacht, leeftijd en tumor stadium. Deze set van kwaliteitsindicatoren kan een basis vormen voor andere oncologische kwaliteitsregistraties.

**Hoofdstuk 3** beschrijft onderzoek naar behoeften en voorkeuren van patiënten met hoofd-halstumoren, met name om de huidige geïntegreerde zorg aan te passen aan een meer patiëntgerichte zorg. Semi-gestructureerde interviews zijn gehouden met 14 huidige en voormalige patiënten en voorzitters van twee Nederlandse hoofd-halstumor patiëntenverenigingen om alle mogelijke behoeften en voorkeuren te identificeren. De gevonden behoeften en voorkeuren zijn vervolgens gecategoriseerd met behulp van het acht-dimensionale Picker-model voor patiëntgerichte zorg. In totaal zijn 34 thema's en voorkeuren geïdentificeerd en gecategoriseerd in het Picker-model. Thema's die vaker voorkwamen zijn: 1) behoefte aan gepersonaliseerde zorg met aandacht voor de waarden van de patiënt; 2) duidelijk inzicht in het zorgproces op organisatorisch niveau; 3) gebruik van gepersonaliseerde communicatie, onderwijs en informatie die voldoet aan de behoeften van patiënten; 4) adequate betrokkenheid van

paramedici voor lichamelijke ondersteuning; 5) het vergroten van de aandacht voor de impact van hoofd-halstumoren en de behandeling ervan in de maatschappij; 6) adequate ondersteuning voor familie en vrienden; 7) adequate betrokkenheid van de huisarts bij de nazorg; en 8) vermindering van de wachttijd. Het monitoren van de geïdentificeerde thema's in geïntegreerde hoofd-halstumor zorg stelt ons in staat om beter te reageren op de behoeften en voorkeuren van patiënten waardoor de patiëntgerichtheid van de oncologische zorg kan worden verbeterd.

## Eerste resultaten van de kwaliteitsregistratie

**Hoofdstuk 4** beschrijft de huidige zorg voor patiënten met een hoofd-halstumor aan de hand van de geselecteerde kwaliteitsindicatoren (zie hoofdstuk 2). Met name de variatie tussen Nederlandse ziekenhuizen en de invloed van patiënt- en ziekenhuiskenmerken hierop zijn beschreven. Benodigde data voor het berekenen van scores van de kwaliteitsindicatoren zijn verkregen door zelfregistratie van 1.667 curatief behandelde patiënten in acht ziekenhuizen. Een multilevelanalyse is gebruikt om de variatie tussen Nederlandse ziekenhuizen te verklaren en de invloed van patiënt- en ziekenhuiskenmerken te analyseren. De kwaliteit van de huidige zorg varieerde tussen de verschillende ziekenhuizen. De indicator voor de aanwezigheid van een behandelplan had bijvoorbeeld de hoogste score (bij gemiddeld 95% van de patiënten is aan de indicator voldaan) en de variatie tussen ziekenhuizen was klein, namelijk 88-98%. Aan de andere kant, de indicator voor de aanwezigheid van een case manager of verpleegkundige bij het overleg om het behandelplan met de patiënt te bespreken had de laagste score (29%) en een grote variatie tussen ziekenhuizen, namelijk 0-90%. Op patiëntniveau zijn hogere indicator scores geassocieerd met een betere performance status, een verder gevorderd tumor stadium en de aanwezigheid van tumoren in de mondholte en orofarynx. Dit betrof met name de indicatoren voor de betrokkenheid van een tandarts voorafgaand aan de radiotherapie, de doorlooptijd van binnenkomst in een ziekenhuis tot het afronden van diagnostiek binnen 21 kalenderdagen en de start van de behandeling binnen 30 kalenderdagen en voor screening op ondervoeding. Op ziekenhuisniveau zijn hogere indicatorscores geassocieerd met meer curatief behandelde patiënten (volume) voor de indicatoren over het registreren of de patiënt volgens het protocol is behandeld, de doorlooptijd van verwijzing naar het ziekenhuis binnen 7 kalenderdagen en het afronden van diagnostiek binnen 21 kalenderdagen. Hoewel de kwaliteitsregistratie pas recent is gestart, geeft het al variatie in de zorg weer tussen de verschillende ziekenhuizen. Echter, er zijn meer gegevens nodig om stabielere resultaten te verkrijgen voor het gebruik van de registratie bij kwaliteitsverbetering.

Monitoren hoe patiënten zich voelen en wat patiënten ervaren tijdens het zorgproces, geeft zorgverleners mogelijkheden om de zorg te verbeteren. In **hoofdstuk 5** zijn meer specifieke verbeteringsaspecten verkregen voor verschillende behandelingsmethoden door het meten van patiënt gerapporteerde uitkomsten (PRO's) en patiënt gerapporteerde ervaringen (PRE's) voor

zowel patiënten met één behandelmodaliteit (bijvoorbeeld alleen een operatie) als met patiënten met meerdere modaliteiten (bijvoorbeeld operatie en bestraling). Gevalideerde PRO-vragenlijsten (PROM's), met onder andere de globale gezondheidsstatus, functionele scores en symptoomscores (EORTC-C30 & H & N35) zijn afgenomen voorafgaand aan en op 3, 6 en 12 maanden na de laatste behandeling. De PRE-vragenlijst (PREM) (gebaseerd op de CQ-index), met vragen over bijvoorbeeld de organisatie van zorg en samenwerking van zorgverleners, is afgenomen op 12 maanden na de diagnose. Beschrijvende analyses zijn gebruikt om de trends in PRO's over de tijd te beoordelen en om het verschil tussen mono- en multimodaliteitsbehandeling van PRO's en PRE's te bepalen. Uit deze studie is gebleken dat patiënten met multimodaliteitsbehandeling een minder goed georganiseerd zorgproces hebben ervaren, slechtere functionele scores hadden en ook meer symptomen hadden dan patiënten met een monomodaliteitsbehandeling. Daarnaast hadden patiënten met alleen radiotherapie lagere functionele scores en meer symptomen dan patiënten met alleen een operatie. Gezien de hogere incidentie van symptomen en verlies van functioneren bij patiënten na een multimodaliteitsbehandeling, moet de nazorgfase meer op maat georganiseerd worden en gericht zijn op herstel van functie en het verminderen van symptomen.

## **Audit en feedback**

**Hoofdstuk 6** beschrijft een onderzoek naar de (verschillen in) voorkeuren van belanghebbenden van de DHNA wat betreft het terugrapporteren van de resultaten uit de kwaliteitsregistratie. Er zijn semi-gestructureerde interviews gehouden met in totaal 37 patiënten, medisch specialisten, paramedici en zorgverzekeraars. Alle belanghebbenden gaven aan dat terugkoppeling de gezondheidszorg kan verbeteren door bewustwording, zelfreflectie en reflectie op lotgenoten of collega's en door benchmarking. Patiënten zijn geïnteresseerd in het ontvangen van terugkoppeling over de zorg die zij daadwerkelijk ontvangen hebben, terwijl medisch specialisten en zorgverzekeraars voornamelijk geïnteresseerd zijn in uitkomsten van de zorg. Alle geïnterviewde belanghebbenden hadden de voorkeur voor het gebruik van een staafdiagram voor het terugkoppelen van resultaten. Patiënten hadden de voorkeur voor een taartdiagram voor PRO's en PRE's; de Kaplan Meier curve had de voorkeur van medische specialisten voor overlevingscijfers. Geïnterviewden hebben aangegeven dat terugrapportages eenvoudig moeten zijn met eerst een globaal overzicht van alle cijfers en worden bij voorkeur 1-4 keer per jaar verzonden per e-mail. Tenslotte, patiënten en zorgverleners hebben aangegeven dat ze voorzichtig zijn met het naar buiten brengen van gegevens. Uit deze verkennende studie blijkt dat voorkeuren op het gebied van terugrapportages verschillen tussen belanghebbenden.

**In hoofdstuk 7** zijn de belangrijkste bevindingen van dit proefschrift besproken aan de hand van recente literatuur, waarna de implicaties voor toekomstig onderzoek, klinische praktijk en beleidsvorming zijn besproken.





## INDICATORENSETS

### ***Verschillend aantallen indicatoren in voorgaande hoofdstukken***

De eerste set indicatoren bestond uit 40 kwaliteitsindicatoren; vijf uitkomstindicatoren vanuit beide perspectieven, 13 en 19 procesindicatoren vanuit respectievelijk de medisch specialist en de paramedicus en drie structuurindicatoren vanuit het perspectief van de paramedicus. Discussie bleef bestaan over de indicatoren vanuit het perspectief van logopedist waarna na één jaar nieuwe indicatoren zijn ontwikkeld. Dit resulteerde in een totaal van 18 procesindicatoren vanuit het perspectief van de paramedicus. Op dit moment bestaat de uiteindelijke set indicatoren uit 39 indicatoren. Om deze rede worden verschillende aantallen indicatoren genoemd in hoofdstuk 1, 4 en 7.



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## Indicatorenset Kwaliteitsregistratie Hoofdhalsketen - Medisch specialisten

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### Uitkomstindicatoren

Van de patiënten met een hoofd-halstumor die in opzet curatief behandeld zijn in een Hoofd-Hals Oncologisch Centrum (inclusief preferred partner) wordt het percentage patiënten bepaald.....

1. .. waarbij **de status NED, AWD, DOD, DID, DTC of Dead**
  - a) 1 jaar na afronding van de behandeling is geregistreerd;
  - b) 2 jaar na afronding van de behandeling is geregistreerd;
  - c) 3 jaar na afronding van de behandeling is geregistreerd;
  - d) 4 jaar na afronding van de behandeling is geregistreerd;
  - e) 5 jaar na afronding van de behandeling is geregistreerd;
  - f) 1 t/m 5 jaar na afronding van de behandeling is geregistreerd.

(NED = No evidence of disease; AWD = Alive with disease; DOD = Dead of disease; DID = Dead of intercurrent disease (*disease at the same time*); DTC = Dead of treatment complications)

(Richtlijn/literatuur: Input expert panel)

- 2.1 .. waarbij het **eerste residu, metastase of 2e primaire is opgetreden binnen 5 jaar** na afronding van de in opzet curatieve behandeling. (Richtlijn/literatuur: Input expert panel)

Van de patiënten met een hoofd-halstumor die in opzet curatief behandeld zijn in een Hoofd-Hals Oncologisch Centrum (inclusief preferred partner) waarbij het eerste recidief is opgetreden binnen 5 jaar na de in opzet curatieve behandeling wordt het percentage patiënten bepaald.....

- 2.2 .. waarbij het **recidief residu, metastase of 2e primaire gespecificeerd** is met betrekking tot
  - a) de histologie;
  - b) rTNM status;
  - c) localisatie van het recidief
  - d) kenmerk a t/m c.

(Richtlijn/literatuur: Input expert panel)

Van de patiënten met een hoofd-halstumor die in opzet curatief behandeld zijn in een Hoofd-Hals Oncologisch Centrum (inclusief preferred partner) wordt het percentage patiënten bepaald.....

3. .. waarbij **een complicatie is opgetreden** na behandeling met
  - a) radiotherapie (vroeg complicaties)
  - b) radiotherapie (late complicaties)
  - c) chemotherapie
  - d) chirurgie

(Richtlijn/literatuur: Input expert panel)

→ *de complicaties voor radiotherapie en chemotherapie worden op een later moment meegenomen*

### Kwaliteit van leven

De kwaliteit van leven van patiënten met hoofd-halstumoren kan gemeten worden met drie instrumenten. Het voorstel is om de generieke kwaliteit van leven te meten met EuroQoL-5D en de specifieke kwaliteit van leven met de EORTC-QLQ-C30, aangevuld met de QLQ-hn35. Er wordt een baseline meting van de kwaliteit van leven gedaan voordat de patiënt start met de behandeling. Hierna wordt de vragenlijst 3, 6, 12 en 24 maanden na afronden van de laatste behandeling afgenomen. De laatste vragenlijst wordt afgenomen vijf jaar na het afronden van de laatste behandeling.

### Patiëntervaringen

Voor het meten van de patiëntervaringen is het voorstel om een verkorte versie van de CQ-index 'zorg voor patiënten met kanker' te gebruiken en de eerste versie van CQ-index radiotherapie als pilot. De CQ-index radiotherapie wordt 6 maanden na diagnose afgenomen, de oncologische CQ-index 'zorg voor patiënten met kanker' wordt 12 maanden na diagnose afgenomen.

### **Indicatoren Diagnostiek**

Van de patiënten met een hoofd-halstumor waarbij diagnostiek is uitgevoerd of gereviseerd in een Hoofd-Hals Oncologisch Centrum (inclusief preferred partner) en een in opzet curatief behandeladvies heeft gekregen waarbij pathologie-onderzoek is uitgevoerd of gereviseerd op een biopt, resectiepreparaat of resectiepreparaat van de hals wordt het percentage patiënten bepaald...

4 .. waarbij door de patholoog **de onderstaande specifieke kenmerken zijn geregistreerd.**

(Richtlijn/literatuur: CCO/ NWHHT/ SIGN/ Hessel et al., 2010)

- *Specifieke kenmerken resectiepreparaat primaire tumor zijn: Tumor grootte in mm; Infiltratie diepte in mm; Marge status in mm; Patroon van infiltratie; Perineurale of vaso- invasieve groei; Speciaal type (bijv acontholytisch); HPV status bij OPC en Differentiatiegraad*

- *Specifieke kenmerken resectiepreparaat hals zijn: Aantal lymfeklieren bekeken; Aantal positieve lymfeklieren; Level van betrokken lymfeklieren; Extracapsulaire uitbreiding van metastasen en Diameter grootste metastase*

- *Specifieke kenmerken biopt zijn: HPV status bij OPC en Differentiatiegraad*

→ *deze indicator wordt door PALGA geregistreerd en niet door de centra/preferred partners zelf.*

Van de patiënten met een hoofd-halstumor waarbij diagnostiek is uitgevoerd of gereviseerd in een Hoofd-Hals Oncologisch Centrum (inclusief preferred partner) en een in opzet curatief behandeladvies heeft gekregen wordt het percentage patiënten bepaald...

5. .. waarbij **de patiënt voorafgaand aan de behandeling besproken is in het MDO van een Hoofd-Hals**

**Oncologisch Centrum.** (Richtlijn/literatuur: CCO/ HNTCSS/ IGZ / NICE/ SIGN/ Hessel et al., 2010)

Van de patiënten met een hoofd-halstumor waarbij diagnostiek is uitgevoerd of gereviseerd in een Hoofd-Hals Oncologisch Centrum (inclusief preferred partner) en een in opzet curatief behandeladvies heeft gekregen en besproken is in het MDO van een Hoofd-Hals Oncologisch Centrum voorafgaand aan de behandeling wordt het percentage patiënten bepaald...

6. .. waarbij **de hoofdbehandelaar aanwezig was bij het MDO.** (Richtlijn/literatuur: IGZ)

→ *deze indicator wordt op een later moment meegenomen*

7. .. waarbij **de ondersteunende specialismen en ondersteunende disciplines A t/m F aanwezig waren.**

(Richtlijn/literatuur: IGZ)

*(Benodigde ondersteunende specialismen zijn: A. Twee erkende specialisten met ervaring in reconstructieve chirurgie in het hoofd-halsgebied; B. Twee erkende specialisten in de radiotherapie met ervaring in het hoofd-halsgebied; C. Eén erkend patholoog met ervaring in de pathologie van het hoofd-halsgebied; D. Eén medisch oncoloog; E. Eén radioloog / nucleair geneeskundige; en F. Eén oncologieverpleegkundige of één casemanager).*

→ *deze indicator wordt op een later moment meegenomen*

8. .. waarvoor **een behandelplan is opgesteld.** (Richtlijn/literatuur: IGZ)

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Van de patiënten met een hoofd-halstumor waarbij diagnostiek is uitgevoerd of gereviseerd in een Hoofd-Hals Oncologisch Centrum (inclusief preferred partner), die een in opzet curatief behandeladvies hebben gekregen, besproken zijn in het MDO van een Hoofd-Hals Oncologisch Centrum voorafgaand aan de behandeling en waarvoor een behandelplan is opgesteld wordt het percentage patiënten..

9. .. waarbij onderstaande **punten 1 & 2 zijn opgenomen in het behandelplan**. (Richtlijn/literatuur: IGZ)  
(Punten behandelplan: 1. Is het een protocollaire behandeling? & 2. Zijn er overwegingen die leiden tot afwijkingen van het protocol (o.a. patiënt voorkeuren)?

### Indicatoren Behandeling

Van de patiënten met een hoofd-halstumor dat in opzet curatief behandeld is in een Hoofd-Hals Oncologisch Centrum (inclusief preferred partner) zijn en een radiotherapeutische behandeling hebben ondergaan waarbij de mandibula en/of maxilla betrokken zijn in het radiotherapieveld (exclusie T1 glottis carcinomen) wordt het percentage patiënten bepaald....

10. .. waarbij **de patiënt gezien is door een tandheelkundig team** voor start van behandeling met radiotherapie. (Richtlijn/literatuur: CCO/ HNTCSS/ NICE/ NWHHT/ SIGN)

### Indicatoren Nazorg & Follow-up

Van de patiënten met een hoofd-halstumor dat in opzet curatief behandeld is in een Hoofd-Hals Oncologisch Centrum (inclusief preferred partner) zijn en een halsklierdissectie (level I t/m V) hebben ondergaan wordt het percentage patiënten bepaald...

11. .. waarbij **de patiënt is beoordeeld door de fysiotherapeut binnen zeven dagen na dissectie**.  
(Richtlijn/literatuur: HNTCSS/ NWHHT)

Van de patiënten met een hoofd-halstumor dat in opzet curatief behandeld is in een Hoofd-Hals Oncologisch Centrum (inclusief preferred partner) waarbij de schildklier geheel of gedeeltelijk in het bestralingsveld ligt wordt het percentage patiënten bepaald..

12. .. waarbij **de schildklierfunctie is gecontroleerd na afronden van de bestraling** op
- a. 6 maanden na laatste behandeling;
  - a. 12 maanden na laatste behandeling;
  - b. 24 maanden na laatste behandeling;
  - c. 36 maanden na laatste behandeling;
  - d. 48 maanden na laatste behandeling;
  - e. 60 maanden na laatste behandeling;
  - f. 6, 12, 24, 36, 48 & 60 maanden na laatste behandeling
- (Richtlijn/literatuur: NWHHT/ Hessel et al., 2010)

→ deze indicator wordt op een later moment meegenomen

### Indicatoren Coördinatie & Organisatie

Van de patiënten die verwezen zijn naar een centrum door een huisarts of specialist met (verdenking op) een hoofd-halstumor naar een Hoofd-Hals Oncologisch Centrum (inclusief preferred partner) waarbij diagnostiek is uitgevoerd of gereviseerd in een HHOC (inclusief preferred partner) en een in opzet curatief behandeladvies hebben gekregen wordt het percentage patiënten bepaald..

13. .. waarbij **de patiënt terecht kon op de poli** van een Hoofd-Hals Oncologisch Centrum of preferred partner (van 1e lijn naar 2e lijn) **binnen een 'bepaald aantal dagen'**. (Richtlijn/literatuur: Ouwens et al., 2007)

Van de patiënten met een hoofd-halstumor waarbij diagnostiek is uitgevoerd of gereviseerd in een Hoofd-Hals Oncologisch Centrum (inclusief preferred partner) en die een in opzet curatief behandeladvies hebben gekregen wordt het percentage patiënten bepaald..

14. .. waarbij **de diagnostiek na het eerste bezoek** aan het Hoofd-Hals Oncologisch Centrum of preferred partner binnen een **'bepaald aantal dagen' is afgerond** (afonden diagnostiek = het MDO).  
(Richtlijn/literatuur: Input expert panel)

Van de patiënten met een hoofd-halstumor die in opzet curatief behandeld zijn in een Hoofd-Hals Oncologisch Centrum (inclusief preferred partner) wordt het percentage patiënten bepaald....

15. .. waarbij **de behandeling binnen een 'bepaald aantal dagen' is gestart na eerste bezoek** aan het Hoofd-Hals Oncologisch Centrum of preferred partner (norm NWHHT is 80% behandeld binnen 30 dagen).

Van de patiënten met een hoofd-halstumor die in opzet curatief behandeld zijn in een HHOC (inclusief preferred partner) wordt het percentage patiënten bepaald...

16. .. waarbij **een volgende behandeling is gestart binnen een 'bepaald aantal dagen' na voltooiing van eerste behandeling.** (Richtlijn/literatuur: Kelly et al., 2012)

\* tweede behandeling binnen het traject van de primaire behandeling.

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## Indicatorenset Kwaliteitsregistratie Hoofdhalsketen - Paramedici

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### Uitkomstindicatoren

Zie medisch specialisten

### Indicatoren Voedingszorg

Van de patiënten met een hoofd-halstumor waarbij diagnostiek is uitgevoerd of gereviseerd in een Hoofd-Hals Oncologisch Centrum (inclusief preferred partner) en die een in opzet curatief behandeladvies hebben gekregen wordt het percentage patiënten bepaald..

4. .. waarbij door de verpleegkundige is **gescreend op het risico op ondervoeding op:**
  1. bij eerste polibezoek van een Hoofd-Hals Oncologisch Centrum of preferred partner & start chirurgische behandeling
  2. bij eerste polibezoek van een Hoofd-Hals Oncologisch Centrum of preferred partner & start (dag)behandeling (chemo)radiotherapie)

*(Richtlijn: Austr/ N&S/ Oncovoed)*
5. .. waarbij door de diëtist cq verpleegkundige is **gemonitord op ondervoeding** aan de hand van % gewichtsverlies op:
  - a) indien radiotherapie en/of chemoradiatie:
    1. week 3 van de behandeling met radiotherapie en/of chemoradiatie (gelijktijdig toepassen chemotherapie en radiatie)
    2. laatste week van de radiotherapie en/of chemoradiatie behandeling
    3. twee weken tot een maand na de laatste behandeling (ongeachte welke behandeling; op moment van controle bij de arts)
    4. drie maanden na de laatste behandeling (ongeachte welke behandeling)
  - b) indien chirurgie:
    1. twee weken tot een maand na de laatste behandeling (ongeachte welke behandeling; op moment van controle bij de arts)
    2. drie maanden na de laatste behandeling (ongeachte welke behandeling)

*(Richtlijn: Austr/ N&S/ Oncovoed)*

Van de patiënten met een hoofd-halstumor waarbij diagnostiek is uitgevoerd of gereviseerd in een Hoofd-Hals Oncologisch Centrum (inclusief preferred partner) en die een in opzet curatief behandeladvies hebben gekregen waarbij de screeningsuitslag op ondervoeding 'matig risico' of 'hoog risico' is wordt het percentage patiënten bepaald..

6. .. waarbij de patiënt is **doorverwezen naar de diëtist** én waarna een **nutritional assessment is afgenomen** (BMI classificatie en % gewichtsverlies). *(Richtlijn: HHCvoed)*

### Indicatoren Psychosociale zorg

Van de patiënten met een hoofd-halstumor die in opzet curatief behandeld zijn in een Hoofd-Hals Oncologisch Centrum (inclusief preferred partner) waarbij psychologische signalering plaats vindt met de Lastmeter of Oncoquest wordt het percentage patiënten bepaald..

7. ..waarbij **psychologisch signalering plaats heeft gevonden** op de momenten 1 t/m 4. *(Richtlijn: Hypo/ Larynx/ Mond/ Oncopsy/ input expert panel)*

1. Net na diagnose (vóór start behandeling);
  2. Net na behandeling;
  3. Zes weken na laatste behandeling;
  4. Elke drie maanden na laatste behandeling (*op dit moment in het project is dat nog na drie maanden en na zes maanden*);
8. ..waarbij het **resultaat van de Lastmeter of computersysteem OncoQuest is opgenomen in het (elektronisch) patiëntendossier**. (*Richtlijn: Oncopsy*)

Van de patiënten met een hoofd-halstumor die in opzet curatief behandeld zijn in een Hoofd-Hals Oncologisch Centrum (inclusief preferred partner) met een 'hoog risico' volgens de Lastmeter of computersysteem Oncoquest wordt het percentage patiënten bepaald..

9. ... waarbij met de patiënt de **noodzaak tot verwijzing** naar een psycholoog, psychiatrisch verpleegkundige, maatschappelijk werkster, geestelijke verzorging of psychiater is besproken. (*Richtlijn: HHCvoed/ Hypo/ Larynx/ Mond/ Oncopsy*)

### Indicatoren Mondzorg

Van dentate patiënten met een hoofd-halstumor waarbij diagnostiek is uitgevoerd of gereviseerd in een Hoofd-Hals Oncologisch Centrum (inclusief preferred partner) en die een in opzet curatief behandeladvies hebben gekregen wordt het percentage patiënten bepaald..

10. .. waarbij ter preventie van radiatie cariës voorafgaand aan de radiotherapie **fluoridekappen zijn aangemeten**. (*Richtlijn: Hypo/ Larynx/ Mond*)

Van dentate en edentate patiënten met een hoofd-halstumor waarbij diagnostiek is uitgevoerd of gereviseerd in een Hoofd-Hals Oncologisch Centrum (inclusief preferred partner) en die een in opzet curatief behandeladvies hebben gekregen wordt het percentage patiënten bepaald..

11. .. waarbij ter preventie van weefselbeschadiging, in de vorm van mucositis door verstrooiing van de straling, tijdens de radiotherapie de patiënt de mond frequent (8-10 maal daags) spoelt met een zout/soda oplossing (*Richtlijn: Hypo/ Larynx/ Mond*)

→ Deze indicator zal aan de patiëntenvragenlijst worden toegevoegd en zodoende door de patiënt worden ingevuld.

Voor dentate en edentate patiënten, met kroon en/of brugwerk en/of amalgaam vullingen en/of implantaten, met een hoofdhalstumor waarbij diagnostiek is uitgevoerd of gereviseerd in een Hoofd-Hals Oncologisch Centrum (inclusief preferred partner) en die een in opzet curatief behandeladvies hebben gekregen wordt het percentage patiënten bepaald..

12. .. waarbij voorafgaand aan de radiotherapie **scatteringskappen zijn aangemeten** ter preventie van mucositis. (*Richtlijn Mondholte/ Oro*).

### Indicatoren Lichamelijk functioneren

#### Fysiotherapie

Van de patiënten met een hoofd-halstumor waarbij diagnostiek is uitgevoerd of gereviseerd in een Hoofd-Hals Oncologisch Centrum (inclusief preferred partner) en die een in opzet curatief behandeladvies hebben gekregen en een halsklierdissectie (level I t/m V) heeft ondergaan wordt het percentage patiënten bepaald..

13. .. waarbij een baseline meting en een postoperatieve (binnen 14 dagen na operatie) beoordeling plaats heeft gevonden door een fysiotherapeut op:
- a) Baseline beoordeling voor schouderfunctie en zenuwuitval (NXI);

- 
- b) Postoperatieve beoordeling voor schouderfunctie en zenuwuitval (NXI);
  - c) Baseline beoordeling voor functie van de cervicale wervelkolom;
  - d) Postoperatieve beoordeling voor functie van de cervicale wervelkolom;

*(Richtlijn: Behandelprogre / Halskl)*

Van de patiënten met een hoofd-halstumor die in opzet curatief behandeld zijn in een Hoofd-Hals Oncologisch Centrum (inclusief preferred partner) en een halsklierdissectie (level I t/m V) heeft ondergaan wanneer een patiënt een hoog risicoprofiel voor schouder disability heeft en de patiënt een behandelwens heeft wordt het percentage patiënten bepaald..

14. .. waarbij een gestructureerde vervolgbehandeling plaatsvindt na ontslag door het centrum zelf of dat er een gestructureerde overdracht plaatsvindt. *(Richtlijn: input expert panel)*

Van de patiënten met een hoofd-halstumor die in opzet curatief behandeld zijn een Hoofd-Hals Oncologisch Centrum (inclusief preferred partner) met onder andere een reconstructietechniek (fibulalap bij reconstructie van de kaak) wordt het percentage patiënten bepaald..

15. .. waarbij een **fysiotherapeut in consult** is geroepen door de behandelend arts. *(Richtlijn: Behandelprogre / Halskl/ input expert panel)*

### Logopedie

Van de patiënten met een hoofd-halstumor die in opzet curatief behandeld zijn met een chirurgische behandeling bestaande uit onder andere een reconstructie of een totale larynxextirpatie in een Hoofd-Hals Oncologisch Centrum (inclusief preferred partner) wordt het percentage patiënten bepaald...

16. ..waarbij de patiënt pre-operatief is gezien door de logopedist ivm voorlichting, baseline meting of interventie (conform consensus in expertpanel).

Van de patiënten met een hoofd-halstumor die in opzet curatief behandeld zijn met een chirurgische behandeling bestaande uit onder andere een reconstructie of een totale larynxextirpatie in een Hoofd-Hals Oncologisch Centrum (inclusief preferred partner) wordt het percentage patiënten bepaald...

17. ..waarbij de patiënt vóór ontslag is gezien door de logopedist voor diagnostiek en eerste advies/behandeling van de slik- en/of spraakstoornis of spraakrevalidatie na totale larynxextirpatie (conform consensus in expertpanel).

### **Indicatoren Communicatie & Voorlichting**

Van de patiënten met een hoofd-halstumor die in opzet curatief behandeld zijn of waarbij diagnostiek is uitgevoerd of gereviseerd in een Hoofd-Hals Oncologisch Centrum (inclusief preferred partner) en een in opzet curatief behandeladvies heeft gekregen wordt het percentage patiënten bepaald..

18. ... waarbij met de patiënt en diens familie de gevolgen van roken en alcohol op de ziekte en de noodzaak tot stoppen zijn besproken. *(Richtlijn: input expert panel)*

→ Deze indicator zal aan de patiëntenvragenlijst worden toegevoegd en zodoende door de patiënt worden ingevuld.

### Indicatoren Coördinatie & Organisatie

Van de patiënten met een hoofd-halstumor waarbij diagnostiek is uitgevoerd of gereviseerd in een Hoofd-Hals Oncologisch Centrum (inclusief preferred partner) en die een in opzet curatief behandeladvies hebben gekregen waarbij een uitslaggesprek / slecht nieuwsgesprek plaats vindt wordt het percentage patiënten bepaald..

19. .. waarbij de case manager/ oncologisch verpleegkundige aanwezig was. (*Richtlijn: Input expert panel/ SlechtN*)

Van de patiënten met een hoofd-halstumor die in opzet curatief behandeld zijn in een Hoofd-Hals Oncologisch Centrum (inclusief preferred partner) wordt het percentage patiënten bepaald..

20. .. waarbij een transmurale overdracht van patiënteninformatie is geweest vanuit klinische paramedici naar de eerste lijn. (*Richtlijn: Oncovoed*)

Van de patiënten met een hoofd-halstumor waarbij diagnostiek is uitgevoerd of gereviseerd in een Hoofd-Hals Oncologisch Centrum (inclusief preferred partner) en die een in opzet curatief behandeladvies hebben gekregen wordt het percentage patiënten bepaald..

21. .. waarbij de case manager/oncologisch verpleegkundige aanwezig is bij het MDO van een Hoofd-Hals Oncologisch Centrum. (*Richtlijn: IGZ*)

### Indicatoren ziekenhuisniveau

Bij de patiënten met een hoofd-halstumor die in opzet curatief behandeld zijn in een Hoofd-Hals Oncologisch Centrum (inclusief preferred partner) wordt het percentage centra bepaald..

22. ..waarbij de **score en het beloop van de Lastmeter/ OncoQuest goed toegankelijk zijn voor alle behandelars**. (*Richtlijn: Oncopsy*)
23. ..waarbij **een case manager/oncologisch verpleegkundige minimaal 4 dagen per week op de poli aanwezig is**. (*Richtlijn: Input expert panel/ IGZ*)
24. .. waarbij er **op de poli 1 FTE verpleegkundige aanwezig is voor de opvang van 100 nieuwe HHO patiënten**. (*Richtlijn: Input expert panel, IKNL*)
- Indicatoren 22 t/m 24 zijn structuur indicatoren die één keer per centra/ziekenhuis geïnventariseerd word





## **DANKWOORD**

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## DANKWOORD

Ik heb onwijs genoten van mijn promotietraject en onwijs veel geleerd. Ik heb zeker een paar keer symbolisch de computer uit het raam gegooid omdat het allemaal stom was maar vaker was mijn instelling: 'Oké, dan wassen we dit varkentje ook nog even'. Waarschijnlijk waren deze eigenschappen al deels aanwezig in mij maar....heel cliché.... ook ik wil graag mijn promotieteam bedanken. Hoe verder ik in mijn promotietraject kwam, hoe meer ik me realiseerde dat ik erg geboft heb. Ik heb menig persoon zien stoppen, maar ik heb nooit het idee gehad dat ik alleen stond. Rosella: iedere maandag stond ik trouw bij jouw deur te wachten met een lijstje met punten. Gewoon om even te sparren en te checken of ik op de goede weg zat. Ik beseft nu dat ik best verwend ben! En hoe ik een stuk gecorrigeerd terug kreeg?! Vaak voor de helft rood, maar met allemaal goede punten waar niemand anders mee kwam en waarvan ik had gehoopt dat ik het zelf had gezien. Robert, jouw reactiesnelheid is er één om jaloers op te zijn. Ondanks dat je KNO arts bent, en keteneigenaar, en in allerlei commissies zit, en ga zo maar even door, kreeg ik altijd een snelle en concrete reactie. Als ik 's avonds nog iets stuurde kreeg ik de volgende dag altijd het eerst van jou een reactie, zo rond 7.00u. Zeker niet te vergeten is Thijs, ik stond er altijd van te kijken hoe jij precies wist hoe de vork in de steel zat en welke issues er speelden. Politieke discussies wist je met mooie woorden altijd goed op te vangen en de angel eruit te halen. En Ludi, ik heb jou vaak telefonisch gesproken of via Skype gezien. Dank voor je verfrissende blik op stukken tekst en artikelen. Kort maar krachtig gaf je je mening en soms net even anders dan de anderen. Al met al, fijn dat jullie er voor mij waren!

Voor mijn onderzoek heb ik verschillende ervaringsdeskundigen persoonlijk mogen spreken. Dit was voor mij van grote meerwaarde en dit heeft zeker het onderzoek en de audit naar een hoger niveau getild. Daarnaast heeft de stuurgroep, eerst onder leiding van Richard Grol en daarna onder leiding van Jetty Hoeksema, een enorme inzet getoond. Zonder jullie kritische feedback en motivatie hadden we nu niet gestaan waar we op dit moment staan. Tevens wil ik graag de deelnemende ziekenhuizen en de gemandateerde leden bedanken, ook jullie hebben soms hemel en aarde bewogen om dit project van de grond te krijgen.

Daarnaast is er nog een legio aan mensen die ik wil bedanken en die mij de gelegenheid hebben gegeven om mijn eigen pad te gaan. Wytske: tijdens mijn hele promotietraject ben je mijn kamergenoot geweest, we hebben door de jaren heen veel gedeeld met elkaar: zowel leuke als minder leuke dingen. Andere kamergenootjes: Arna, Marijke, Myrna, Tessa, Dana, Anne, Tsjiske en Sander: dank voor alle lunches, etentjes, gesprekken, grappen etc! Eva: ik ken je al vanuit de studie, toen kwamen we elkaar weer tegen bij Epic en vervolgens weer bij IQ. Altijd in voor iets creatiefs of een ludieke actie (#paaseieren verstoppen met Wytske). Deze twee mede-paashazen: dank dat jullie mijn paranimfen willen zijn! En natuurlijk heb ik nog een heleboel fijne collega's vanuit 'de kelder', hier hebben we vele uurtjes samen gezeten: jullie ook ontzettend bedankt

voor alle borrels, uitjes, intervisie en goede gesprekken! Niet alleen de kelder, maar natuurlijk ook een aantal personen 'van boven'. Jozé; jij hebt veel bijgedragen aan het project en het onder de aandacht gebracht bij de NFU. Mariëlle; op verschillende nevenprojecten heb ik met jou mogen samenwerken en onder andere veel geleerd over standaardisering. Ik heb veel van jullie beide geleerd op verschillende vlakken en ik heb het altijd een prettige samenwerking gevonden!

Omdat ik mezelf breder wilde verdiepen, heb ik op de valreep gesolliciteerd voor de UMC raad. Top plan! Toen ik eenmaal snapte waar het over ging kon ik meepraten en voelde ik me echt onderdeel van een heuse adviesraad voor het Radboudumc. Dank voor deze ervaring!

Nu mijn vrienden in Nijmegen, 'thuis' of elders in het land: altijd mocht ik jullie updaten met de stand van zaken. Soms over leuke dingen en soms even mijn hart luchten en gewoon even zeuren. Maar bovenal hebben jullie mijn leven naast promoveren verrijkt.

Mam, jij hebt de advertentie voor in de krant al 4 maanden klaarliggen. Na een paar keer uitleggen, wist je waar ik mee bezig was en wat zo'n traject precies inhoudt. Nu de verdediging zelf nog, en dan weet je alles! Pap, mama hield jou altijd goed op de hoogte en af en toe kreeg ik zelf een vraag over hoe het ging. Maar met name voor andere levensbeslissingen zoals verhuizen, nieuw laminaat, lamp ophangen etc. stapte jij zonder moeite in de auto om naar Nijmegen of 's-Hertogenbosch te rijden. Jullie lieten me altijd mijn eigen weg gaan onder het thema 'niks moet, alles mag'. Helaas moeten er soms toch een heleboel dingen, ook in een promotietraject, maar ik heb van kleins af aan voldoende ruimte gekregen om mijn eigen pad te gaan.

Cynthia en Martin, ik gaf jullie zo nu en dan een update over de zussen-en-broer-app. Als we elkaar tegen kwamen ging het gesprek soms niet over het promoveren, en soms juist heel uitgebreid. Dank voor jullie interesse de afgelopen jaren!

Thalia, jij hebt toch wel het meest meegekregen in de afgelopen jaren. Wekelijks hangen we aan de telefoon voor van alles en nog wat, maar zeker ook over promotiezaken. Sorry dat ik soms wat kortaf was omdat ik niet de tijd nam om een issue fatsoenlijk uit te leggen terwijl je soms als 'leek' juist een goed idee had. Dank voor je luisterend oor, het relativeren en het meedenken!

Last but not least, Jos. Jij kwam pas halverwege het traject binnen en soms met harde leer kwam jij er achter dat promoveren geen 9 tot 5 baan is. Toen we eenmaal samenwoonden stond toch menigmaal de wekker in het weekend al vroeg of liet ik tijdens het avondeten doorschemeren dat ik toch nog graag nog iets aan mijn promotie wilde doen die avond. Dit was met name het geval toen ik in Leiden bij mijn nieuwe baan begon. Maar altijd heb jij mij gesteund en mijn passie gewaardeerd. Op dat we nu even in rustiger vaarwater zitten, mijn nieuwe uitdaging nog even op zich laat wachten, en dat we samen 80 worden!



## **CURRICULUM VITAE**



## **CURRICULUM VITAE**

Lydia van Overveld is op 4 januari 1988 geboren in Bergen op Zoom, samen met haar tweelingzusje. Ze groeide op in Hoogerheide in een gezin van vier kinderen. In 2006 behaalde zij haar VWO diploma aan de Roncalli Scholengemeenschap te Bergen op Zoom, waarna ze startte met de opleiding Biomedische Wetenschappen in Nijmegen. In haar studietijd heeft ze zich een jaar fulltime ingezet voor het Quaestoraat van de Medische Faculteits Vereniging Nijmegen. Ze begon met de master Pathobiology maar besloot na twee jaar alsnog over te stappen naar de master Health Technology Assessment. Tweemaal is ze naar het buitenland gegaan tijdens haar studie, eenmaal voor een Pathobiology stage naar Argentinië en in het laatste jaar voor haar masterstage naar Engeland. In Engeland heeft ze onderzoek gedaan naar het verband tussen een te hoog bloedsuikergehalte (glucosegehalte) en ongunstige perinatale uitkomsten met behulp van statistische analyses en een meta-analyse. Na haar afstuderen heeft ze kort als trainer voor het nieuwe patiëntendossier, Epic, in het Radboudumc gewerkt.

In november 2013 is Lydia begonnen aan haar promotietraject bij IQ healthcare waarin ze een kwaliteitsregistratie heeft opgezet voor patiënten met een hoofd-halstumor. Het eindresultaat is dit proefschrift en een landelijke audit die nu is ondergebracht bij DICA. Tijdens haar promotietraject heeft Lydia zich ingezet voor de belangen van promovendi, onder andere bij RIHS PhD council, UGV en de landelijke UMC werkgroep. De grootste neventaak op dit gebied was de UMC Raad. Daarnaast heeft ze meegewerkt aan verschillende projecten voor het verminderen van registratielast: Registratie aan de Bron. Sinds mei 2017 is ze werkzaam als teamleider bij DICA in Leiden. Ze woont samen met Jos Welling in 's-Hertogenbosch.





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