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Patients' and healthcare professionals' perspectives on better use of patient-reported outcome measures in head and neck cancer

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Health Policy Analysis

Patients' and Healthcare Professionals' Perspectives on Better Use of Patient-Reported Outcome Measures in Head and Neck Cancer



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ABSTRACT

Objectives: Patients with head and neck cancer (HNC) are often highly affected by disease and treatment, resulting in impaired physical functioning and quality of life. Therefore, evaluation of patients' psychosocial and functional outcomes can be facilitated by patient-reported outcome measures (PROMs). By providing the patients' own perspectives, PROMs are crucial to improving patient-centered care. This study aimed to improve understanding of the perceived value of PROMs in HNC care and how to optimize their clinical value based on patients' and multidisciplinary healthcare professionals' (HCPs) perspectives.

Methods: Population-based surveys among patients with HNC through their patient association and among HCPs nationwide through the Dutch Head and Neck Audit.

Results: A total of 54 patients and 40 multidisciplinary HCPs from all 14 nationwide HNC centers (100%) responded. For patients, the most important element of patient-reported outcome collection systems was including a call to action for those with worse-than-average scores (28%), whereas clinicians found discussing scores during clinical visits the most important (39%). Although 16% of clinicians found short completion time the most important element, none of the patients selected completion time as most important. Additionally, 17% of patients stated completion time was not an issue, provided clinicians would use the outcomes for clinical purposes.

Conclusions: Although patients and clinicians acknowledged the value of patient-reported outcomes, patients would like to be more involved in the clinical implications of their outcomes. Enhancing patients' involvement by a call to action and providing feedback on their scores during outpatient clinic visits may improve the clinical value of PROMs.

Keywords: head and neck cancer, implementation research, patient-reported outcomes, quality of care, quality registries.

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Introduction

Although survival rates have substantially improved after head and neck cancer (HNC), patients are still affected in numerous ways by their disease and treatment. Head and neck tumors tend to grow fast in functionally and esthetically important regions.^{1–4} Therefore, patients often experience impairment in fundamental functions such as swallowing and eating, and they can have trouble being understood when speaking. Patients may also experience psychosocial impairment because of facial alteration, disfigurement, and public drooling.^{5–8} Measuring such impairments can only be done from the patient's perspective, which may be facilitated through patient-reported outcome measures (PROMs).^{9–12} PROMs are specifically designed questionnaires to adequately measure patient-reported outcomes (PROs). Assessing the patient's perspective through PROMs is crucial to aid patient-centered quality improvement and enhance shared decision making.

The value and relevance of implementing PROMs in daily healthcare practice have extensively been acknowledged by patients and healthcare professionals (HCPs) worldwide.^{10,13–15} In 2014, the Head and Neck Subcommittee of the American National Cancer Institute recommended including quality of life in clinical trials, for example, collected through PROMs.¹⁶ The interest in and the use of PROMs for patients with HNC has grown tremendously since.^{5,17–19} Nevertheless, challenges for PROM data collection are hampering implementation.

The Dutch Head and Neck Audit (DHNA) was set up in 2014 as the first Dutch nationwide quality registry for HNC care that systematically collects data from all hospitals that provide treatment (surgery or adjuvant therapy) for patients with HNC in The Netherlands. It has a 100% participation rate and data are mostly registered by independent registration workers of the Dutch Cancer Registry. This multidisciplinary collaboration involves medical specialists and allied health professionals and includes the possibility for online PROM collection. The goal was to use

these PROMs in routine care during patient follow-up. Nevertheless, where data on treatment and adjuvant therapy are collected completely and successfully, the implementation of PROMs has been challenging. To date, in clinical practice of most hospitals, but also in the international literature, return rates of PROMs in the head and neck population remain low, for reasons not well understood.^{14,20-22} Therefore, successfully addressing PROs throughout the treatment process and thereafter has been difficult when no PRO data are being provided by patients.

The first step in improving patient and HCP participation is to align the goals and experiences of both stakeholders to effectively make use of PROMs.²³ To improve the nationwide collection of PROM data through the DHNA, we conducted this explorative survey on behalf of the 2 most important stakeholders: the patients and HCPs. With this study, we aimed to assess patients' and HCPs' perspectives on PROMs and how best to improve PROM use and collection in clinical practice. The major topics addressed in the survey are the value of PROMs, the current exposure to them, and the optimum system to collect PROMs.

Methods

Study Design

This cross-sectional survey was conducted in The Netherlands as part of an improvement program for PROMs within the nationwide quality registry (DHNA). HCPs from all nationwide centers providing care for patients with HNC are represented within the clinical audit board of the DHNA, thereby covering all centers providing HNC care on a national basis ($n = 14$). Patients are represented in the corresponding society (Patiëntenvereniging Hoofd-Hals [PVHH]), a key umbrella organization of the DHNA that codesigns which indicators are relevant quality-of-care measures for patients with HNC. According to Dutch legislation, this study, as a part of quality-of-care improvement guidance, does not fall under the Medical Research Involving Human Subjects Act scope.

Data Collection Patients

Between August 2020 and February 2021, the patient society for HNC (PVHH) distributed the survey on their official social media account (~1500 members) and in their regular newsletter. All patients connected to the PVHH, who had undergone treatment for mucosal HNC and were familiar with PROMs, were invited to complete the survey. They were asked to participate through the social media post, and this request was also sent once to all people subscribed to their regularly disseminated newsletter.

Data Collection HCPs

The survey was disseminated through the clinical audit board of DHNA during the regular board meetings every quarter of a year. The first invitation was sent during the meeting in December 2019, and in case of no response, a reminder was sent before the next meeting. Between December 2019 and 2020, all clinical audit board members of the DHNA were asked to complete the survey. These board members of the DHNA represent all 14 healthcare centers providing HNC care consisting of HNC surgeons, radiation oncologists, and medical oncologists and represent allied HCPs (nutritionists, case managers, dental hygienists, physical therapists, speech-language pathologists, etc). During weekly multidisciplinary team meetings, all these representatives are adjoined, and all facets are integrated into the care pathway of each patient. Each member of the DHNA was asked to fill in the form and

distribute it to their colleagues involved in the collection and use of PROMs, to further increase the sample size. Requests to fill in and disseminate the survey to colleges were repeated until all 14 centers providing care for these patients had a minimum of one response and all relevant disciplines (nurses, radiotherapists, medical oncologists, head and neck surgeons, and allied HCPs) were represented.

Survey

The survey was set up with a multidisciplinary team involved in the HNC care and PROMs, as part of the DHNA. A digital survey tool was used to make completing the survey as easy as possible for patients and the survey could be filled in anonymously. Questions were modified to the perspective of the patient or the HCP, thereby resulting in 2 different surveys with some overlap to allow for direct comparisons in important areas of interest. Both surveys (Appendix Table 1 in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2023.04.009>) comprised 3 main topics:

1. The value of PROMs and their potential
2. The ideal collecting system for PROMs
3. The current clinical use of PROMs

Within topics 2 and 3, several domains were incorporated: logistics (when, where, and by whom), time investment, monitoring, and evaluation. Five-point Likert scales were used for ordering the importance of various aspects, categorized as not important (-2 and -1), neutral (0), and important (1 and 2). In addition, a single separate question was used to score which of the aspects mentioned earlier were the most and least important.

A cognitive debriefing was performed to ensure the survey its purpose, to assure clear formulation of questions, and prevent unnecessary unclarity for participants.²⁴ In this cognitive debriefing, 6 patients and former patients, 10 HCPs (nurses, medical doctors, and allied HCPs), and 5 secondary or tertiary educated people ($n = 21$ in total) tested the survey. They provided feedback before the final survey was sent to the study sample. Wording and option sets were adjusted accordingly. A variety of closed questions—with a Likert scale, single or multiple answers—and open questions were used. The patient version was simplified in formulations and contained more open questions, allowing more room for elaboration. After these adjustments, this version was debriefed with the patients' society. This revised version was then agreed upon during a consensus meeting with the PVHH chair and 4 HCPs (H.R., D.Y.A., L.S., and D.d.J.). The survey was drafted through a digital form. Patients could complete the survey anonymously.

Completion Time

The time it took to complete a standard PROM set from the DHNA was extracted from an ongoing, not yet published, prospective multicenter PROMs study (NKI-AvL institutional review board reference IRBd20-156) within the same patient population. The first 50 respondents who digitally completed these PROMs—the FACE-Q Head and Neck module, European Organization for Research and Treatment of Cancer Quality of Life Questionnaires (EORTC-QLQ) Head and Neck 35 (EORTC-QLQ-H&N35), and EORTC-QLQ Cancer 30 (EORTC-QLQ-C30)—were randomly selected to extract their time investments. Data on the completion time were adjoined with data on the completion time and analyzed using IBM SPSS V22,0 (IBM Corporations, Armond, NY).

Table 1. Basic characteristics of participants that completed the survey on the current and ideal usage of patient-reported outcome measures in The Netherlands.

Group	Characteristics	n (%)	
Patients with head and neck cancer (representing 100% of centers, n = 54)	Age	< 65 years	29 (54)
		≥ 65 years	25 (46)
	Tumor site	Larynx	21 (39)
		Oral cavity (1 lip)	16 (30)
		Pharynx	8 (15)
		Salivary gland	5 (9)
		Other	4 (7)
	Time since diagnosis	Up to 6 months ago	3 (6)
		6 to 12 months ago	7 (13)
		1 to 2 years ago	15 (28)
		> 2 year ago	29 (53)
	Treatment modalities*	Primary resection	30 (56)
		Reconstructive surgery	13 (24)
(PO)RT		42 (78)	
Systemic therapy		16 (30)	
Other		2 (4)	
Healthcare professionals (100% of centers, n = 36)	Member of the DHNA clinical audit board	Yes	19 (53)
		No	17 (47)
	Discipline	Surgeon*	22 (61)
		Radiotherapist	3 (8)
		Allied professional	3 (8)
		Nurse (practitioner)	2 (6)
		Policy advisor/manager	4 (11)
		Researcher/epidemiologist	2 (6)

DHNA indicates Dutch Head and Neck Audit; (PO)RT, (post operative) radiation therapy.
*1 or a combination.

Results

Survey Respondents

Patients

A total of 54 patients (Table 1) treated for primary HNC provided a complete response (answered > 80% of applicable items), with a median age of 63 years (range 41–82 years). Most patients were diagnosed of cancer of the larynx (39%), oral cavity (30%), or pharynx (15%). Most patients (81%) were diagnosed >1 year ago, 13% 6 to 12 months ago, and 6% within the last 3 months.

HCP respondents

At least 1 HCP (n = 36) of each of the 14 nationwide centers providing care for patients with HNC, mainly consisting of head and neck surgeons (54%) (Table 1), completed the survey. Nineteen HCPs (51%) were DHNA Clinical Audit Board members. One center had not yet implemented PROMs, whereas in 3 centers PROMs were considered part of the standard of care. In total, a quarter of HCPs are actively using PROMs, mainly in academic centers. In those centers, 75% or more of patients are asked to fill in PROMs, but 31% of HNCs were unaware of local practice and implementation status.

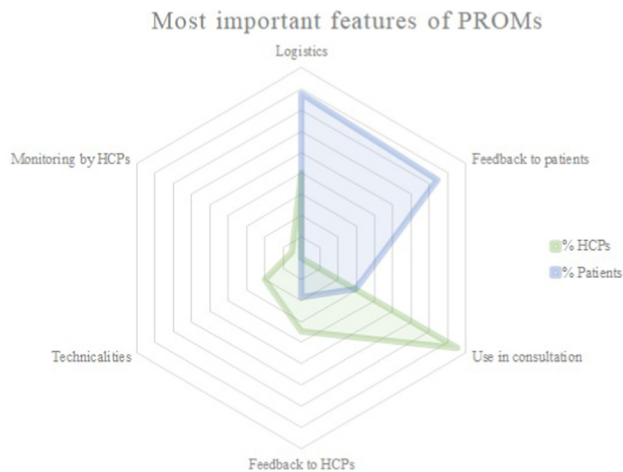
Current Patients' Experience With PROMs in Routine Care

See questions listed in Appendix Table 1—theme “Current use of PROMs”—in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2023.04.009>. When asked about exposure to PROMs during routine care, 37% answered previously having been asked to complete PROMs in their treatment center only once (37%) and 30% at every clinical visit. Of these patients, 84% filled in PROMs multiple times, 57% of whom did on a computer and 48% on article. Most patients completed the routine care PROMs without help from others (93%), and if help was needed, they asked a relative or friend (n = 2) or hospital staff (n = 1). In total, 69% of the participating patients recommend using PROMs in routine care for other patients. Reasons to recommend the use of PROMs are better understanding for HCPs of patients' complaints (n = 17), to put complaints into perspective (n = 9), or to retrieve information on the ordinary course of recovery (n = 12).

The Value of PROs

See questions listed in Appendix Table 1—theme “Value of PROMs”—in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2023.04.009>. When asking patients why PROMs are of

Figure 1. Radar graph of the most important factors for successful implementation of the PROMs from patients' and HCPs perspectives, gathered in 6 domains.



HCP indicates healthcare professional; PROM, patient-reported outcome measure.

value to them, the most selected answers (by 75% of patients) were to enable HCPs to better understand symptoms and complaints and if PROMs seemed relevant for their treatment (69%); 39% of patients used PROMs to better prepare for their consult.

All HCPs except for 1 surgeon ($n = 35$) found PROMs to be of additional value for patients and HCPs.

Ideal PROMs System: Facilitators and Barriers for Valuable PROM Use

In the radar graph (Fig. 1), all facilitators and barriers are summarized per theme for both patient and HCP respondents, and below we elaborate on all questions connected to the topic (see questions in Appendix Table 1—in Supplemental Materials theme “Ideal PROMs system: facilitators and barriers”—found at <https://doi.org/10.1016/j.jval.2023.04.009>).

Patients

Although 32% of respondents stated never having been asked to fill in PROMs, only 3 would not recommend other patients to do so. HCPs could increase patients' motivation to complete PROMs by emphasizing the importance of PROs for patients themselves (50%), for research and improved care for future patients (80%), and by providing real-time feedback on PROs (52%).

Forty-two percent of patients stated they could not think of a valid reason for patients to deny participation to a PRO questionnaire. If they had to think of a reason why other patients would deny participation, they chose a lack of feedback of PROM outcomes or lack of discussing outcomes during their consultation with their HCP (37%), domains that do not apply to the patient (13%), or question with complex wording that patients cannot comprehend (8%).

The overall most important factor for patients (28%) was the integration of a call to action in case they had worse-than-average scores. This call to action, regardless of to whom it is communicated by (eg, office staff, nurses, HCP), was individually labeled as important by 84% of patients. Seeing their scores over time was important to very important for 74% of patients. Comparing themselves with other patients was chosen least frequently as being important (64%).

Regarding logistics, most patients preferred to be asked to complete PROMs by the physician involved in their diagnosis and treatment. For most of them (76%), their doctor or case manager was the best option. The timing for asking patients to participate in PROMs did not match the current standard. Currently, patients are often asked to participate during their diagnosis consult (in agreement with 19% of respondents' preference), for 50% of patients, an invitation before their consult would be desirable, and for 34% afterward. The majority preferred an electronic data collection system for PROMs, regardless of whether this is done with or without assistance on a smartphone, iPad, or computer, preferably at home (65%).

HCPs

Only 67% of HCPs stated they actively motivate patients to fill in PROMs. They stated that patients with no interest in PROMs (67%), too long completion time (42%), and illiteracy or a language barrier (28%) are the most likely reasons for patients not to complete a PROM. The lack of feedback to patients was noted as a barrier by 8% for completing a PROM the first time and by 23% for continuing to do so.

Providing feedback to patients on their PRO scores was the most important in 93%. Other factors with a majority of high importance were the ability for HCPs to compare the patient with other patients (80%) and the call to action for HCPs (74%), followed by a call to action for patients (70%). None of the HCPs selected the “call to action” to patients as the most important factor, and 8% even saw it as the least important factor overall. Implementing PROMs in the multidisciplinary team meeting was important to 65%, and implementation in the DHNA to 63% of HCPs.

Patients' Time Investment

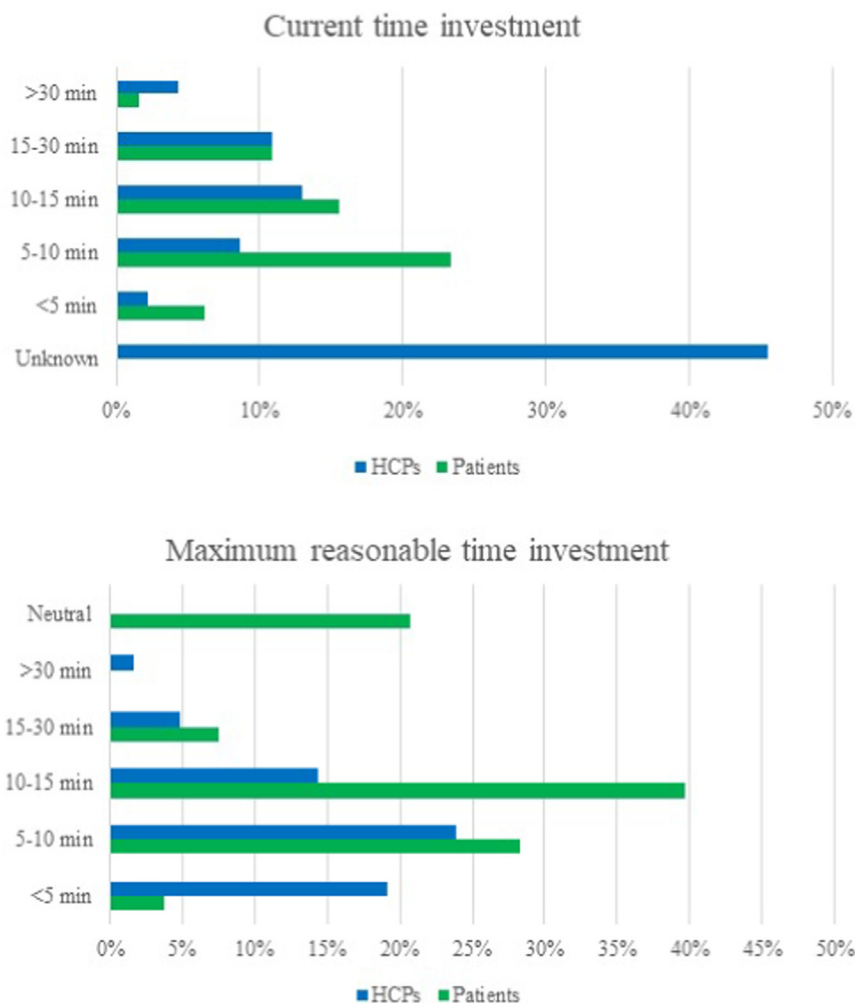
Median PROM completion time (Fig. 2) was 9 minutes (interquartile range [IQR] 7-11) for the FACE-Q, 3 minutes (IQR 2-4) for the EORTC-QLQ-H&N35, and 2 minutes (IQR 2-4) for the EORTC-QLQ-C30. As stated by 48% of patients within this study, a maximum time investment of 10 to 30 minutes was reasonable. Besides, 21% of patients did not set a maximum if clinicians were to discuss the PRO scores at the next consultation (Fig. 3).

For HCPs, the maximum acceptable time for patients to complete PROMs was considered to be up to 5 minutes in 29%, 5 to 10 minutes in 37%, and 10 to 15 minutes in 24% for HCPs. Although 15% of patients stated that an unreasonable completion time was a solid reason to not complete a PROM, for 20% the completion time was not an issue if the outcomes were used accordingly (Fig. 3A, green).

Discussion

Although most HCPs and patients consider PROMs as a valuable tool to measure patients' outcomes, implementation of PROMs during routine care remains challenging. In this explorative survey, we found that the value of PROMs seemed clear to patients and HCPs alike. Nevertheless, there was a different point of view regarding the elements essential to increasing the value of PROMs during treatment and clinical follow-up. For patients, the most important facilitators were integrating a call to action for patients with worse-than-average scores. Thus, to increase the value and response rates of PROMs, HCPs should keep in mind that patients want a call to action based on their scores. Another aspect thought to be important in designing, choosing, and implementing PROMs is the amount of time that patients are asked to spend completing the questionnaires. Although many

Figure 2. Boxplot of the time it took HNC patients to fill in the 3 PROMs: FACE-Q, European Organization for Research and Treatment of Cancer Quality of Life Questionnaires (EORTC-QLQ) Head and Neck 35 (H&N35), and Cancer 30 (C30). The horizontal line represents the maximum reasonable time investment (up to 15 minutes or more) according to 69% of patients. Time registration was measured in minutes per instrument based on data of an ongoing multicenter PROMs study in the Netherlands (reference IRBd20-156). The FACE-Q consists of 13 PROM subscales, represented as 1 instrument.



C30 indicates Cancer 30; EORTC-QLQ, European Organization for Research and Treatment of Cancer Quality of Life Questionnaires; FACE-Q, Head and Neck Cancer Module; H&N35, Head and Neck 35; HNC, head and neck cancer; min, minutes; PROM, patient-reported outcome measure.

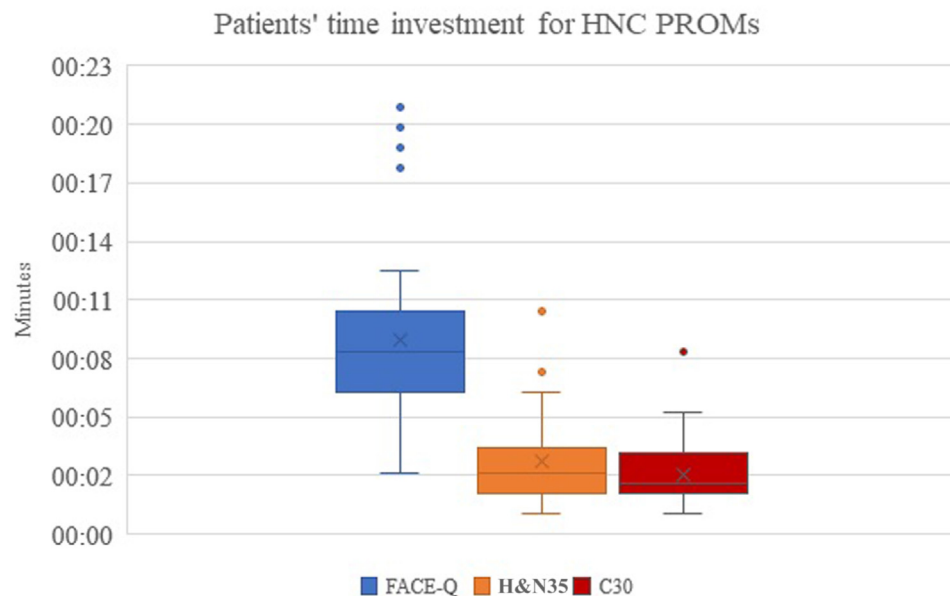
HCPs found that minimizing time patients spend on completing the PROMs was the most important, patients stated that they do not mind longer completion times if data are used to improve their care.

PROMs have shown to enable earlier detection of symptoms and to improve communication between clinicians and patients.²⁵ In line with a systematic qualitative review by Easpai et al (2020),²⁶ we confirmed the positive sentiment of HCPs toward PROMs, and the implementation of PROMs in clinical practice was also found to be important. Although 60% of patients did not use PROMs to prepare for their consultation, 50% of patients preferred an invitation to complete PROMs before their consultation. Inviting patients beforehand may enhance optimal use during consultations, thus increasing the value both for patients and care provider.²⁶ Although PROMs cannot be effectively implemented in routine care without a proper infrastructure,²⁷ further logistical challenges seemed less important to our respondents. In using PROs during routine

clinical consultations, a call to action in case of outlier outcomes was significantly appreciated, especially by patients. Simultaneously, appropriate interventions should be available to offer when outcomes are alarming, to enhance clinical value for both parties.²⁶

PROMs can be used locally and nationally, such as for national quality registries, including the DHNA. Our survey results show that from both perspectives, integration of PROM scores at a local level—of a single patient—outweighs its use at a national level and should thus be prioritized. After local implementation, innovative strategies can be combined and adjoined with clinical data for national quality-of-care comparison purposes, also providing feedback to individual centers. Uniform and focused interpretation of the European Union current privacy legislation, the General Data Protection Regulation,²⁸ should lead to more frequent and more effective implementation of connected data of clinical value and data on PROs at both national and personal levels. This will lead to a wide array of possibilities in personalized medicine and

Figure 3. Perceived current (top) and maximum reasonable (bottom) time investment of patients to fill in PROMs from patients' (green) and HCPs (blue) perspective.



C30 indicates Cancer 30; FACE-Q, Head and Neck Cancer Module; H&N35, Head and Neck 35; HCP, healthcare professional; HNC, head and neck cancer; min, minutes; PROM, patient-reported outcome measure.

quality-of-care improvement initiatives, for example, by trials-within-cohorts strategies.

In current practice and quality-of-care evaluations through the DHNA, the EORTC-QLQ-C30 and H&N35 are the most commonly used PROMs in The Netherlands for patients with HNC.^{4,7} Estimations of the current time investment by patients and HCP were in agreement. Interestingly, almost half of HCPs could not provide an estimate of patients' current time investment. Although HCPs emphasize the need to minimize the time burden, enhancing patients' participation and thus their value seems to primarily rely on using PROs during consultation based on patients' perspectives. Today's time demand for patients to fill out the current PROM sets seemed acceptable to 98% of patients. Complementary FACE-Q subscales that were thought to be of additional value by both parties—"smiling" and "appearance"—were recently added, resulting in a total mean time burden of 7 to 8 minutes for patients to complete the questionnaire set. In light of our findings, this addition can be considered within the margin of reasonable time effort for patients.

The coronavirus disease 2019 pandemic has highlighted the need for better patient monitoring options without the need for in-hospital visits. Thus, PROMs seem more relevant and valuable to explore than ever before. This study's results are relevant to designing the ideal PROM data collection system, optimizing its clinical value, and ensuring that patients and HCP align on how they feel PROMs should be used in routine care.

Although our respondents represented perspectives from patients and HCPs throughout all centers in The Netherlands, the sample sizes remained small and quantitative analysis was not possible. It seems likely that mainly active patients with sufficient resources and computer skills have responded. Nevertheless, these patients are also the most likely to actively participate and fill in PROMs in clinical practice now and in the near future. Therefore, despite its limitations, this explorative survey study can provide valuable guidance on enhancing the value of PROMs to patients, especially at an early implementation phase.

Conclusions

Although both parties acknowledged the value of PROMs, patients would like to be involved in the clinical implications of their outcomes, more than clinicians expected. Implementation in routine care should be the starting point rather than as part of a nationwide quality-of-care initiative. Patients would like to see a call to action if their scores are worse than average. Therefore, they prefer discussing PROM scores during their outpatient visits.

Supplemental Materials

Supplementary data associated with this article can be found in the online version at <https://doi.org/10.1016/j.jval.2023.04.009>.

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Provision of study materials or patients: DHNA study group

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