

# Screening for psychological distress in follow-up care to identify head and neck cancer patients with untreated distress

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## Abstract

**Purpose** The purpose of the study is to investigate screening in follow-up care to identify head and neck cancer (HNC) patients with untreated psychological distress.

**Methods** From November 2009 until December 2012, we investigated the use of OncoQuest (a touch screen computer system to monitor psychological distress (Hospital Anxiety and Depression Scale (HADS)) and quality of life (HRQOL; EORTC QLQ-C30 and H&N35 module) in routine follow-up care. Patients who screened positive for psychological distress (HADS-T >14, HADS-A >7, or HADS-D >7) were asked whether they received psychological or psychiatric treatment. **Results** During the study period of 37 months, OncoQuest was used by 720 individual HNC patients, of whom 714 had complete HADS data. Psychological distress was present in 206 patients (29 %). Of those patients who fulfilled in- and exclusion criteria ( $n=137$ ), 25 received psychological treatment (18 %). Receipt of psychological treatment was significantly related to a higher score on the HADS total scale (19.6 vs. 16.9;  $p=0.019$ ), a lower (worse) score on the EORTC QLQ-C30 scale emotional functioning (46.0 vs. 58.6;  $p=0.023$ ), a higher (worse) score on fatigue (58.2 vs. 46.4;  $p=0.032$ ), problems with sexuality (44.1 vs. 34.4;  $p=0.043$ ), oral pain (43.8 vs. 28.8;  $p=0.011$ ) and speech problems (37.0 vs. 25.3;  $p=0.042$ ).

**Conclusions** Screening for psychological distress via OncoQuest is beneficial because 82 % of HNC patients identified with an increased level of distress who do not yet receive mental treatment were identified. Patients who did receive treatment reported more distress and worse quality of life, which may be explained because patients with more severe problems maybe more inclined to seek help or might be detected easier by caregivers and referred to supportive care more often.

**Keywords** Head and neck cancer · Oncology · Screening for psychological distress · Anxiety · Depression

## Introduction

Psychosocial care is increasingly recognised as an integral part of quality cancer treatment [1]. In the Netherlands, government policy statements, various cancer specific guidelines, reflect broad scientific and societal support for a structured, integrated approach to psychosocial care for cancer patients [2, 3]. Although there is evidence that psychosocial care is effective [4–6], referral rates are low [7, 8], and many patients have unmet needs, related to e.g. fatigue, sexuality issues and life stress [9–11]. The identification and support of cancer patients with psychological distress is a challenge [10, 12], especially in head and neck cancer (HNC) patients as they do not usually express their emotions spontaneously in front of the oncologists. One of the main barriers to deliver psychosocial cancer care in cancer patients is lack of screening for psychological distress in clinical practice to identify patients [13–16].

Fitch [15] stated that the need for identifying psychological distress is clear and there are suitable patient reported outcome measures (PROMs) available to perform this screening. The

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Distress Thermometer with the accompanying problem list is often used for assessment of each patient's unique needs [3, 17]. Other tools have emerged as well, such as Viewpoint [18], SupportScreen [19], ESRA-C [20], and CHES [21]. At the Department of Otolaryngology-Head and Neck Surgery of VU University Medical Center, efficient screening for distress followed by triage to care has become available in 2006 by a touch screen computer system (OncoQuest) that was implemented in routine clinical practice [7, 22, 23]. Via OncoQuest, patients complete quality of life (HRQOL) questionnaires (EORTC QLQ-C30 and condition-specific modules such as the EORTC QLQ-H&N35) and the Hospital Anxiety and Depression Scale (HADS) [23]. OncoQuest is linked to the hospital patient information system. Data are processed in real-time and a care coordinator (a nurse specialised in HNC) can view the results by clear graphics on a computer in the consulting room and discuss these with the patient. In this prospective surveillance model, HRQOL can be repeatedly monitored and changes can be assessed; physical impairment, functional limitations and psychosocial distress can be identified in an early stage, information and psychoeducation can be provided, and, if necessary, supportive care including rehabilitation, psychosocial care and healthy lifestyle programs can be introduced.

Several studies have shown that using PROMs facilitates communication about patients' symptoms, functioning and distress between doctors, nurses and patients [16]. However, an international debate has emerged concerning screening for psychological distress in clinical practice with authors with solid arguments in favour of screening [12, 16, 24–27] and other authors with valid arguments against it [28–30]. For instance, Palmer et al. [29] reported that 36 % of recently diagnosed breast cancer patients with elevated distress or a psychiatric disorder already received psychotropic medication. The authors argued that because of this relatively high percentage, screening all breast cancer patients is therefore not very effective. However, information on patients with other types of cancer is scarce, which hampers the discussion on pros and cons of screening for distress in clinical practice.

The aim of this study is to investigate screening in follow-up care to identify HNC patients with untreated psychological distress. Furthermore, sociodemographic and clinical factors and HRQOL outcomes will be investigated that may be associated with untreated psychological distress.

## Materials and methods

### Study population

All patients who routinely visited our outpatient clinic for follow-up care within a time frame of 37 months (November 2009–December 2012) were screened for psychological

distress as part of standard clinical care. Patients who screened positive for psychological distress (HADS-T >14, HADS-A >7, or HADS-D >7) were assessed for eligibility for this cross-sectional study and, when eligible, asked to participate in one interview on whether they received psychiatric or psychological treatment, and if so, which type of treatment. Eligible patients were those who were treated for cancer at least 1 month to 15 years earlier in VU University Medical Center for carcinoma of the lip, oral cavity, oropharynx, hypopharynx, nasopharynx, larynx or salivary glands (all stages), and who were treated with curative intent (all treatment modalities). Exclusion criteria were other (neurological) diseases causing cognitive dysfunction, end of treatment for a psychiatric disorder less than 2 months ago or being under treatment for another psychiatric disorder, not being reachable, insufficient knowledge of the Dutch language to fill out the questionnaires, and incomplete HADS data. Sociodemographic (age, gender) and clinical variables (tumour site and stage, treatment modality) were assessed by medical records audit.

The Medical Ethics Committee of the VU University Medical Center in Amsterdam approved this study. All procedures followed were in accordance with the Helsinki Declaration of 1975, as revised in 2008, and in accordance with local laws and regulations.

### Screening for distress

Since 2008, we offer all new HNC patients to use a touch screen computer system (OncoQuest) to complete the HADS and the EORTC QLQ-C30 and H&N35 HRQOL questionnaires and to consult a specialised nurse, during follow-up visits after cancer treatment. If needed, a volunteer supports HNC patients using the computer system. Based on the results of OncoQuest (available in real-time in clear graphics on a computer screen), the nurse can identify and support HNC patients with psychological distress or problems regarding (HNC specific) HRQOL. On average, it takes 9 min to complete OncoQuest and the consultations with the nurse are estimated to take 10 min [7, 22, 23].

The HADS is a 14-item self-assessment scale for measuring distress (total HADS score (HADS-T)) with two subscales, anxiety (HADS-A) and depression (HADS-D). The HADS was specifically designed for use in the medically ill [31]. The total HADS score ranges from 0 to 42, the subscales from 0 to 21. A score of >7 on the anxiety scale, a score of >7 on the depression scale and/or a total HADS score of >14 is used as an indicator of a high level of psychological distress [31, 32].

The 30-item EORTC QLQ-C30 (version 3.0) includes a global HRQOL scale (2 items) and comprises five functional scales: physical functioning (5 items), role functioning (2 items), emotional functioning (4 items), cognitive functioning (2 items) and social functioning (2 items). There are three symptom scales (nausea and vomiting (2 items), fatigue (3

items) and pain (2 items) and six single items relating to dyspnoea, insomnia, loss of appetite, constipation, diarrhoea and financial difficulties. The scores of the QLQ-C30 are linearly transformed to a scale of 0–100, with a higher score indicating a higher (i.e., more positive) level of functioning or global HRQOL, or a higher (i.e., more negative) level of symptoms or problems [33, 34].

The EORTC QLQ-H&N35 module covers specific HNC issues and comprises seven subscales: pain (4 items), swallowing (5 items), senses (2 items), speech (3 items), social eating (4 items), social contact (5 items) and sexuality (2 items). There are 11 single items covering problems with teeth, dry mouth, sticky saliva, cough, feeling ill, opening the mouth wide, weight loss, weight gain, use of nutritional supplements, feeding tubes, and painkillers. The scores of the QLQ-H&N35 are linearly transformed to a scale of 0–100, with a higher score indicating a higher (i.e., more negative) level of symptoms or problems [35]. In the present study, the scales and the first six single items were used.

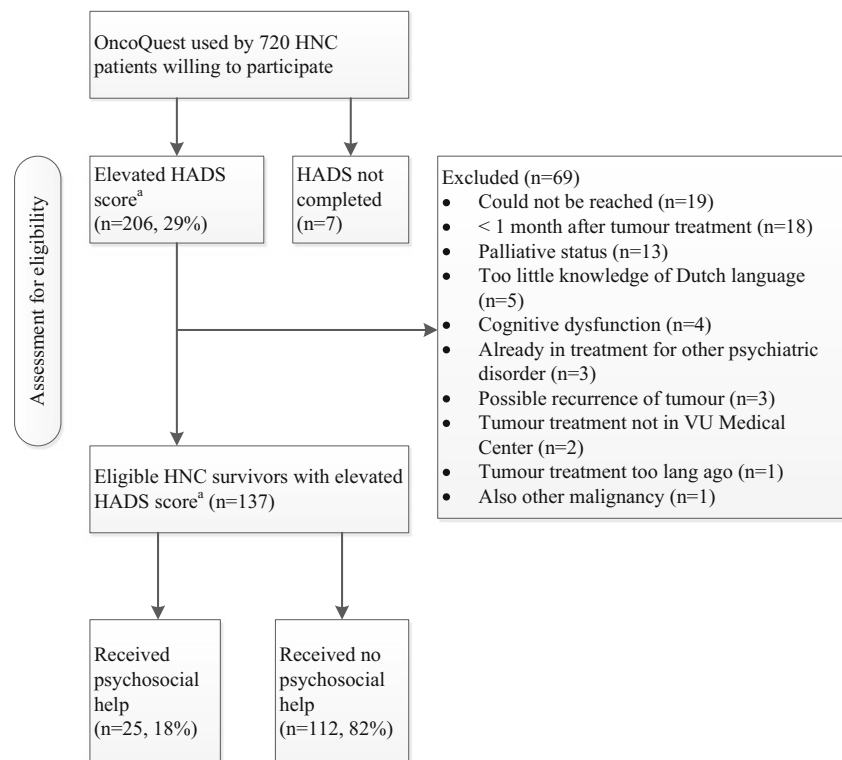
### The value of screening

In the present study, eligible HNC patients in follow-up care with an increased level of psychological distress (HADS-T >14, HADS-A >7, or HADS-D >7) were asked whether they received psychiatric or psychological treatment. Based on

earlier research [7, 36], it was expected that in clinical practice, 25–30 % of HNC patients would present with psychological distress of whom the majority do not receive psychological treatment. Screening for distress in follow-up care was defined to have added value if at least 50 % of HNC patients diagnosed with psychological distress did not yet receive psychological or psychiatric treatment.

To provide information on sociodemographic, clinical factors and HRQOL variables possibly associated with untreated psychological distress, several univariate analyses were performed. Chi-square tests were used to investigate whether gender (male vs. female), tumour location (lip/oral cavity, oropharynx, hypopharynx/larynx, other), tumour stage based on the UICC TNM classification of malignant tumours (I, II, II, IV), treatment modality (single treatment (surgery or radiotherapy) vs. combination (surgery and (chemo)radiation)) or time since treatment (1–12 months vs. >12 months) were associated with untreated psychological distress. Independent *t* tests or, in case of skewness, Mann-Whitney tests were used to investigate whether age, HADS-T, HADS-A, or HADS-D or the EORTC QLQ-C30 and H&N35 subscales were associated with untreated psychological distress. All analyses were performed using the IBM Statistical Package for the Social Science (SPSS) version 20 (IBM Corp., Armonk, NY, USA). For all statistical analyses, a *p* value <0.05 was considered statistically significant.

**Fig. 1** Selection of patients



<sup>a</sup>Elevated HADS score = HADS-A > 7, HADS-D > 7 and/or HADS-total > 14

## Results

### Prevalence of distress and receipt of treatment

During the study period of 37 months, OncoQuest was used by 720 HNC patients in follow-up care, of whom 714 had complete HADS data. Figure 1 shows the flow diagram of the selection of patients. Among the 714 HNC patients, 206 patients screened positive for psychological distress (29 %). Of these 206 patients, 69 patients were excluded: 19 could not be reached, 18 were treated less than 1 month earlier, 13 were in the palliative phase of the disease, 5 had insufficient knowledge of the Dutch language, 4 had a cognitive dysfunction, 3 were currently under treatment for a psychiatric disorder other than anxiety or depression, 3 had possible tumour recurrence, 2 had not received treatment at VU University Medical Center, 1 had received tumour treatment too long ago, and 1 also had another untreated malignancy.

Among the 137 HNC patients who screened positive for psychological distress during the study period and fulfilled the

in- and exclusion criteria, 25 (18 %) received psychiatric or psychological treatment: 10 received counselling and psychomedication, 7 received psychomedication, 4 received counselling, and 1 received self-help and psychomedication, 3 patients did not provide information about their treatment.

### Factors related to receipt of psychological or psychiatric treatment

Sociodemographic and clinical characteristics of the study population ( $n=137$ ) are provided in Table 1, and regarding patient reported outcome measures (HADS, EORTC QLQ-C30 and H&N35) in Table 2.

Receipt of psychological or psychiatric treatment (vs. no receipt) was not significantly related to gender, age, tumour location, tumour stage, tumour treatment and time since treatment (Table 1). Receipt of psychological or psychiatric treatment (vs. no receipt) was significantly related to a higher score on the HADS total scale (19.6 vs. 16.9;  $p=0.019$ ), a lower (worse) score on the EORTC QLQ-C30 scale emotional

**Table 1** Overview of sociodemographic and clinical characteristics of the study sample

	Total sample ( $n=137$ ) <i>N</i>	Received no psychosocial care ( $n=112$ ) <i>N</i> (%)	Received psychosocial care ( $n=25$ ) <i>N</i> (%)	<i>p</i> value
Gender				0.92
Male	92	75 (81.5)	17 (18.5)	
Female	45	37 (82.2)	8 (17.8)	
Mean age (SD)	61.7 (10.1)	61.9 (9.8)	61.0 (11.1)	0.74
Tumour location				0.55
Lip/oral cavity	34	29 (85.3)	5 (14.7)	
Oropharynx	36	28 (77.8)	8 (22.2)	
Hypopharynx/larynx	46	36 (78.3)	10 (21.7)	
Other (e.g. parotis)	21	19 (90.5)	2 (9.5)	
Tumour stadium				0.31
I	32	29 (90.6)	3 (9.4)	
II	28	20 (71.4)	8 (28.6)	
III	31	25 (80.6)	6 (19.4)	
IV	41	33 (80.5)	8 (19.5)	
Unknown	5	5 (100.0)	0 (0.0)	
Tumour treatment				0.99
Single	82	67 (81.7)	15 (18.3)	
Surgery	23	19 (82.6)	4 (17.4)	
Radiotherapy	59	48 (81.4)	11 (18.6)	
Combination	55	45 (81.8)	10 (18.2)	
Chemoradiation	25	21 (84.0)	4 (16.0)	
Surgery and (chemo)radiation	30	24 (80.0)	6 (20.0)	
Time since treatment				0.53
1–12 months	57	48 (84.2)	9 (15.8)	
>12 months	80	64 (80.0)	16 (20.0)	

A  $p$  value <0.05 was considered statistically significant

functioning (46.0 vs. 58.6;  $p=0.023$ ), a higher (worse) score on fatigue (58.2 vs. 46.4;  $p=0.032$ ) and problems with sexuality (44.1 vs. 34.4;  $p=0.043$ ), and on the EORTC QLQ-H&N35 scales oral pain (43.8 vs. 28.8;  $p=0.011$ ) and speech problems (37.0 vs. 25.3;  $p=0.042$ ).

## Discussion

The present study revealed that among HNC patients, screening for distress is valuable because of the patients who screened positive for psychological distress (29 %); the majority (82 %)

did not yet receive treatment. This percentage of patients with untreated distress is much higher compared to 64 % among newly diagnosed breast cancer patients as reported by Palmer et al. [29]. Therefore, and because two thirds of patients who screen positive may develop a full-blown depression if left untreated [37], we disagree with Palmer et al. and conclude that screening for distress is beneficial among HNC patients. Our conclusion supports the findings of Kotronoulas et al. [38], who reported in their recent review that routine use of PROMs increases communication about patient outcomes during consultations and that PROMs are associated with improved symptom control, increased supportive care, and patient satisfaction.

**Table 2** Overview of outcomes on HADS, EORTC QLQ-C30 and H&N35, and test statistics of between group differences

		Total sample (N)	Mean	SD	No PC (N)	Mean	SD	PC (N)	Mean	SD	t or Z	df	p value
HADS	Depression	137	8.77	3.61	112	8.42	3.12	25	10.32	5.06	-1.80	28.19	0.082
	Anxiety	135	8.64	3.64	110	8.49	3.64	25	9.28	3.65	-0.98	133.00	0.335
	Total score	135	17.39	5.27	110	16.88	4.79	25	19.60	6.70	-2.37	133.00	0.019
QLQ-C30	Global quality of life	136	58.52	20.37	111	58.93	19.77	25	56.67	23.20	0.50	134.00	0.617
	Physical functioning	135	70.86	21.08	110	72.42	20.28	25	64.00	23.49	1.82	133.00	0.071
	Role functioning	136	60.66	29.30	111	62.76	28.15	25	51.33	32.96	1.78	134.00	0.078
	Emotional functioning	137	56.27	25.08	112	58.56	23.95	25	46.00	27.86	2.299	135.00	0.023
	Cognitive functioning	137	71.41	22.59	112	72.62	21.90	25	66.00	25.22	1.328	135.00	0.186
	Social functioning	135	65.31	25.11	111	66.52	24.77	24	59.72	26.43	1.204	133.00	0.231
	Fatigue	137	48.58	24.88	112	46.43	24.56	25	58.22	24.49	-2.172	135.00	0.03
	Nausea/vomiting	137	12.53	20.19	112	11.90	20.56	25	15.33	18.58	-1.32	n.a.	0.19
	Pain	137	37.47	28.57	112	35.57	28.08	25	46.00	29.77	-1.662	135.00	0.10
	Dyspnoea	136	27.94	28.75	112	28.27	27.66	24	26.39	34.02	0.29	134.00	0.77
	Insomnia	137	37.71	34.02	112	36.31	34.24	25	44.00	32.94	-1.022	135.00	0.31
	Loss of appetite	137	29.93	33.40	112	29.46	33.41	25	32.00	33.99	-0.342	135.00	0.73
	Constipation	137	18.49	26.48	112	19.94	27.75	25	12.00	18.95	-1.11	n.a.	0.27
	Diarrhoea	137	9.98	21.53	112	10.71	22.47	25	6.67	16.67	-0.74	n.a.	0.46
Financial difficulties	137	20.92	28.87	112	21.73	28.55	25	17.33	30.61	-0.99	n.a.	0.32	
QLQ-H&N35	Oral pain	136	31.43	26.45	112	28.79	25.16	24	43.75	29.31	-2.565	134.00	0.01
	Swallowing problems	136	31.62	28.29	112	29.99	28.26	24	39.24	27.75	-1.46	134.00	0.15
	Senses problems	136	28.06	27.79	112	28.72	27.51	24	25.00	29.49	0.594	134.00	0.55
	Speech problems	136	27.37	25.69	112	25.30	24.61	24	37.04	28.88	-2.055	134.00	0.04
	Trouble with social eating	134	34.08	30.36	110	31.74	28.86	24	44.79	35.17	-1.927	132.00	0.06
	Trouble with social contact	135	17.93	19.77	111	16.04	17.32	24	26.67	27.31	-1.48	n.a.	0.14
	Less sexuality	132	40.15	36.89	109	36.54	34.36	23	57.25	44.05	-2.122	27.918	0.04
	Teeth problems	136	24.75	31.95	112	22.62	30.42	24	34.72	37.40	-1.56	n.a.	0.12
	Trouble with opening mouth	136	29.90	33.77	112	27.68	32.23	24	40.28	39.29	-1.67	134	0.10
	Dry mouth	136	51.72	36.47	112	53.27	36.20	24	44.44	37.64	1.077	134	0.28
	Sticky saliva	136	42.40	34.54	112	43.15	34.26	24	38.89	36.34	0.548	134	0.59
	Coughing	136	33.33	29.26	112	33.04	28.47	24	34.72	33.30	-0.255	134	0.80
	Feeling ill	136	30.64	30.91	112	28.87	30.18	24	38.89	33.57	-1.447	134	0.5

In some cases, the total group was smaller than 137 because of missing values

No PC received no psychosocial care, PC received psychosocial care, SD standard deviation, n.a. not applicable

A p value <0.05 was considered statistically significant

Receipt of psychological or psychiatric treatment was significantly related to a higher score on the HADS total scale, a lower (worse) score on the EORTC QLQ-C30 scale emotional functioning, a higher (worse) score on fatigue and problems with sexuality, and on the EORTC QLQ-H&N35 scales oral pain and speech problems. An explanation for these findings might be that patients with more severe problems are more inclined to seek help. But also, these patients might be detected easier by caregivers during follow-up consultation and therefore are referred to supportive care earlier. Carlson et al. reported that full screening (online use of PROMs with a personalised printout of results and a list of contact details of services to help with the identified problems) and triage to care (full screening plus the opportunity to speak with a care professional who could refer to services directly) both result in the most benefit for lung cancer patients, compared to screening alone. Fewer patients in the triage group reported a problem with coping (12.9 %) compared with patients in the minimal (23.9 %) and full (26.9 %) screening groups [26]. Mitchell concluded that screening for distress and monitoring HRQOL in clinical practice is likely to benefit communication and referral for psychosocial help, and that, it has the potential to influence patient well-being but only if barriers are addressed [16]. However, understanding about the complexities of implementing screening programs is still unfolding [15]. In earlier studies, it was argued that incorporating PROMs in clinical practice should aim at equipping health professionals to use patient PROMs data in managing patients, should employ more condition-specific (rather than generic) PROMs, should improve the interpretability of the PROM data feedback to both medical staff and patients, and should support patients to improve their self-efficacy to manage illness-related issues [39]. Recently, key barriers were identified as lack of training and support, low acceptability, and failure to link treatment to the screening results [16]. Also, further implementation research is needed to advance knowledge about the most effective strategies in the context of cancer care [27].

A limitation to our study is that we missed information about the receipt of psychosocial care for 10 % of the participating HNC patients because they could not be reached. However, these patients had mainly borderline HADS scores and additional information about referral to psychological services was not present in their medical dossiers. Therefore, these patients are suspected to not have received any psychosocial treatment. Another limitation of the study is that we do not know whether patients, who did receive treatment, did so as a result of distress screening or whether they already received such treatment. Furthermore, we do not know how many patients, who did not receive psychological treatment or psychiatric treatment (82 %), had unmet psychological care needs. Based on earlier research [40, 41] and clinical practice, our estimation is that many patients with psychological distress do not want to be referred to psychological care. This was

the main reason to start a trial on stepped care in which patients are offered low-intensity interventions like self-help first, before being referred to a psychologist or psychiatrist [42]. Although OncoQuest is valued by the coordinating nurse and by patients, not all eligible patients make use of OncoQuest, which may have resulted in selection bias. A mixed method study including qualitative and quantitative research measures is ongoing and will provide detailed insight into possible barriers and facilitators enabling optimization of OncoQuest. In their randomised clinical trial, Carlson et al. [43], examining the impact of screening for distress followed by personalised triage versus computerised triage, concluded that the best model of screening may be to incorporate personalised triage for patients indicating high levels of depression and anxiety while providing computerised triage for others. Further research is needed on best-practice approaches for implementing sustainable and acceptable screening for distress and triage programs in clinical settings.

## Conclusion

Screening for psychological distress among HNC patients is beneficial to identify patients with psychological distress who do not yet receive treatment. Via OncoQuest, a broad spectrum of HRQOL is monitored (EORTC QLQ-C30 and QLQ-HN35 module), enabling identification of not only psychological distress but also of other problems.

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**Compliance with ethical standards** The Medical Ethics Committee of the VU University Medical Center in Amsterdam approved this study. All procedures followed were in accordance with the Helsinki Declaration of 1975, as revised in 2008, and in accordance with local laws and regulations.

**Conflict of interest** The authors declare that they have no competing interests.

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