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# The Carcinologic Handicap Index: validation of the upgraded version and ability to highlight head and neck cancer patients' needs



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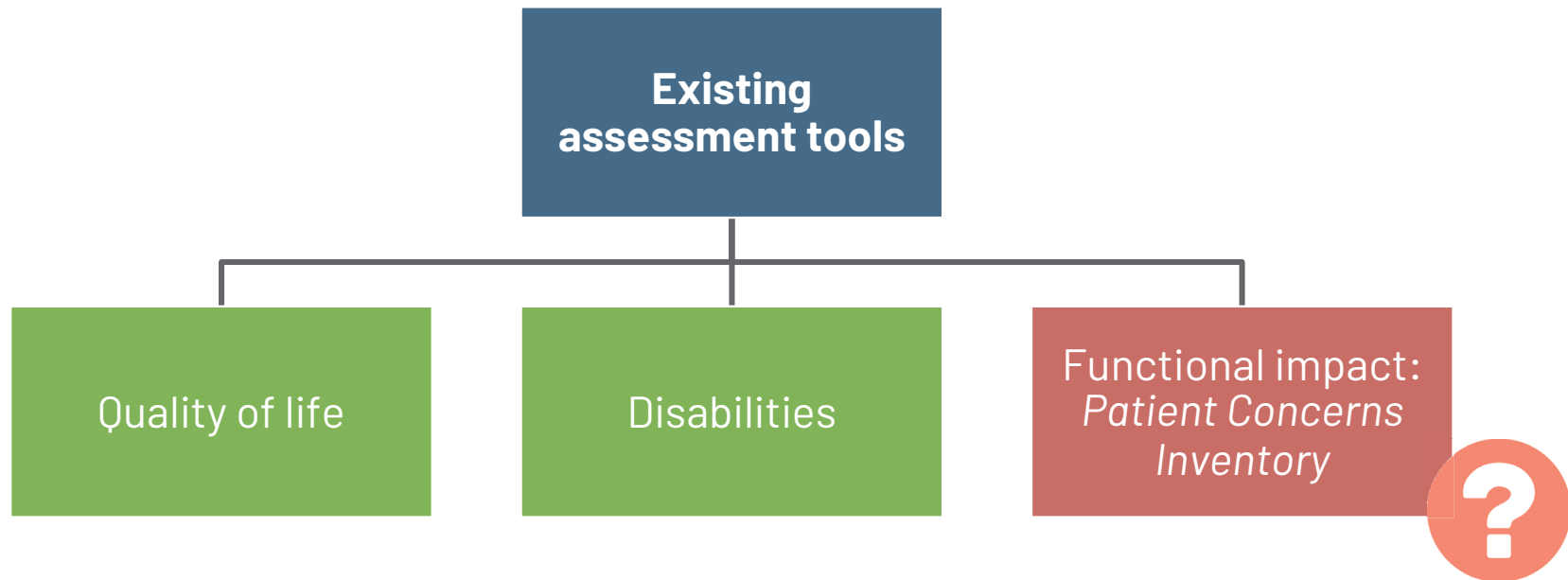
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# Context

Need to take into account the quality of life of cancer patients



Rogers, S. N., El-Sheikha, J., & Lowe, D. (2009). The development of a Patients Concerns Inventory (PCI) to help reveal patients concerns in the head and neck clinic. *Oral Oncology*, 45(7), 555–561. <https://doi.org/10.1016/j.oraloncology.2008.09.004>

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Mlynarek, A., Rieger, J., Harris, J., O'Connell, D., Al-Qahtani, K., Ansari, K., ... Seikaly, H. (2008). Methods of functional outcomes assessment following treatment of oral and oropharyngeal cancer: review of the literature. *J Otolaryngol Head Neck Surg*, 37(1), 2–10.

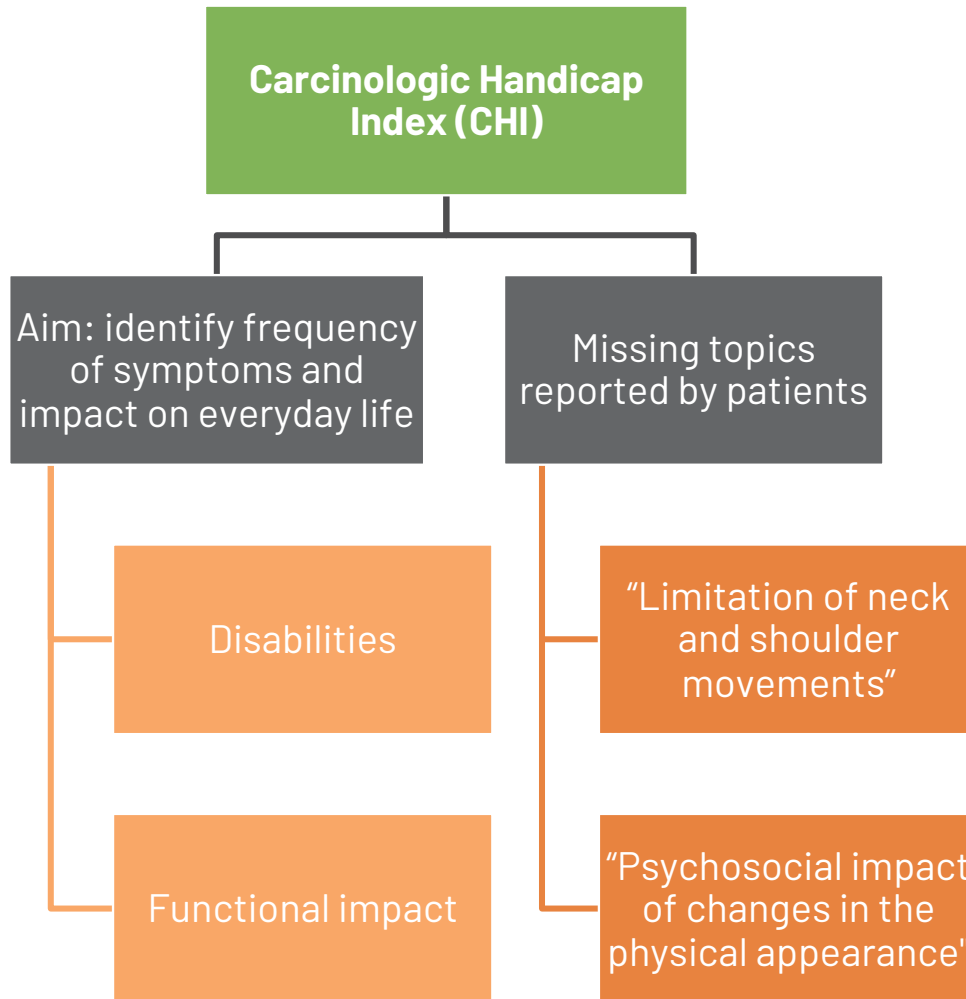
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Borggreven, P. A., Verdonck-De Leeuw, I. M., Muller, M. J., Heiligers, M. L. C. H., De Bree, R., Aaronson, N. K., & Leemans, C. R. (2007). Quality of life and functional status in patients with cancer of the oral cavity and oropharynx: Pretreatment values of a prospective study. *European Archives of Oto-Rhino-Laryngology*, 264(6), 651–657. <https://doi.org/10.1007/s00405-007-0249-5>

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IALP 2019 – THE CARCINOLOGIC HANDICAP INDEX. COMPLETED VERSION

# Context



IALP 2019 - THE CARCINOLOGIC HANDICAP INDEX. COMPLETED VERSION

## DISABILITY SELF-ASSESSMENT

Surname: \_\_\_\_\_ First name: \_\_\_\_\_ Date: \_\_\_\_\_

N = never  
 AN = almost never  
 S = sometimes  
 AA = almost always  
 A = always

		N	AN	S	AA	A
P1	Do you take medication for pain?					
P2	Do you wake up at night because of pain?					
P3	Are you hindered in your activities by pain?					
P4	Do you have pain attacks?					
<b>P (pain)</b>						
S1	Do you have discomfort swallowing?					
S2	Do you ever choke eating or drinking?					
S3	Do you have liquid or solid reflux after meals?					
S4	Do you have problems chewing?					
<b>S (swallowing)</b>						
F1	Do you need to change the texture of food to swallow it?					
F2	Do you take longer eating due to difficulty in swallowing?					
F3	Do you need to enrich your food?					
F4	Have you lost weight?					
<b>F (feeding)</b>						
R1	Do you have difficulty breathing at rest?					
R2	Do your breathing problems restrict your physical activity?					
R3	Do you feel congested?					
R4	Do you need to be semi-seated to sleep?					
<b>R (respiration)</b>						
PH1	Do you have difficulty speaking?					
PH2	Do people have difficulty understanding you?					
PH3	Do you speak less with your family, friends, neighbors?					
PH4	Do you have difficulty articulating?					
<b>PH (phonation)</b>						
H1	Do you ask people to repeat?					
H2	Do you have problems following a conversation in noise?					
H3	Do you have problems understanding over the phone?					
H4	Do you have sounds in your ears?					
<b>H (hearing)</b>						
V1	Do you have difficulty seeing in the shade?					
V2	Do you see less well at a distance or close up?					
V3	Are you bothered by dazzle or floaters in your eyes?					
V4	Has your visual field shrunk?					
<b>V (vision)</b>						
OG1	Do you have difficulty smelling?					
OG2	Are you afraid of having an accident because of your difficulty smelling?					
OG3	Do you have difficulty tasting food?					
OG4	Do you feel frustrated by your difficulty smelling and tasting?					
<b>OG (olfaction-gustation)</b>						
PS1	Is your personal and social life limited by problems related to your illness?					
PS2	Has your illness affected your relationship with other people?					
PS3	Are you bothered by problems related to your illness?					
PS4	Do you feel handicapped by your illness?					
<b>PS (psychosocial)</b>						
<b>TOTAL</b>						

Balaguer, M., Percodani, J., & Woisard, V. (2017). The Carcinologic Handicap Index (CHI): A disability self-assessment questionnaire for head and neck cancer patients. *European Annals of Otorhinolaryngology, Head and Neck Diseases*. <https://doi.org/10.1016/j.anorl.2017.06.010>

# Objectives

## Main objective

Validate the upgraded version  
of the questionnaire

## Secondary objective

Study the link between  
the outcomes  
of the questionnaire  
and the actual expectations  
of patients in terms of care

# Materials and Methods

9 dimensions from the first version of the CHI:

**Sensory functions: 4**

**Upper aerodigestive tract functions: 4**

**Psychosocial impact: 1**

2 **new dimensions** in the French version:

*Items elaborated with carers and patients*

*Pretest phase*

Subjects - Inclusion criteria:

Patients with head and neck related complaints

Healthy controls

## AUTOEVALUATION DU HANDICAP (CHI)

Nom : \_\_\_\_\_ Prénom : \_\_\_\_\_ Date : \_\_\_\_\_

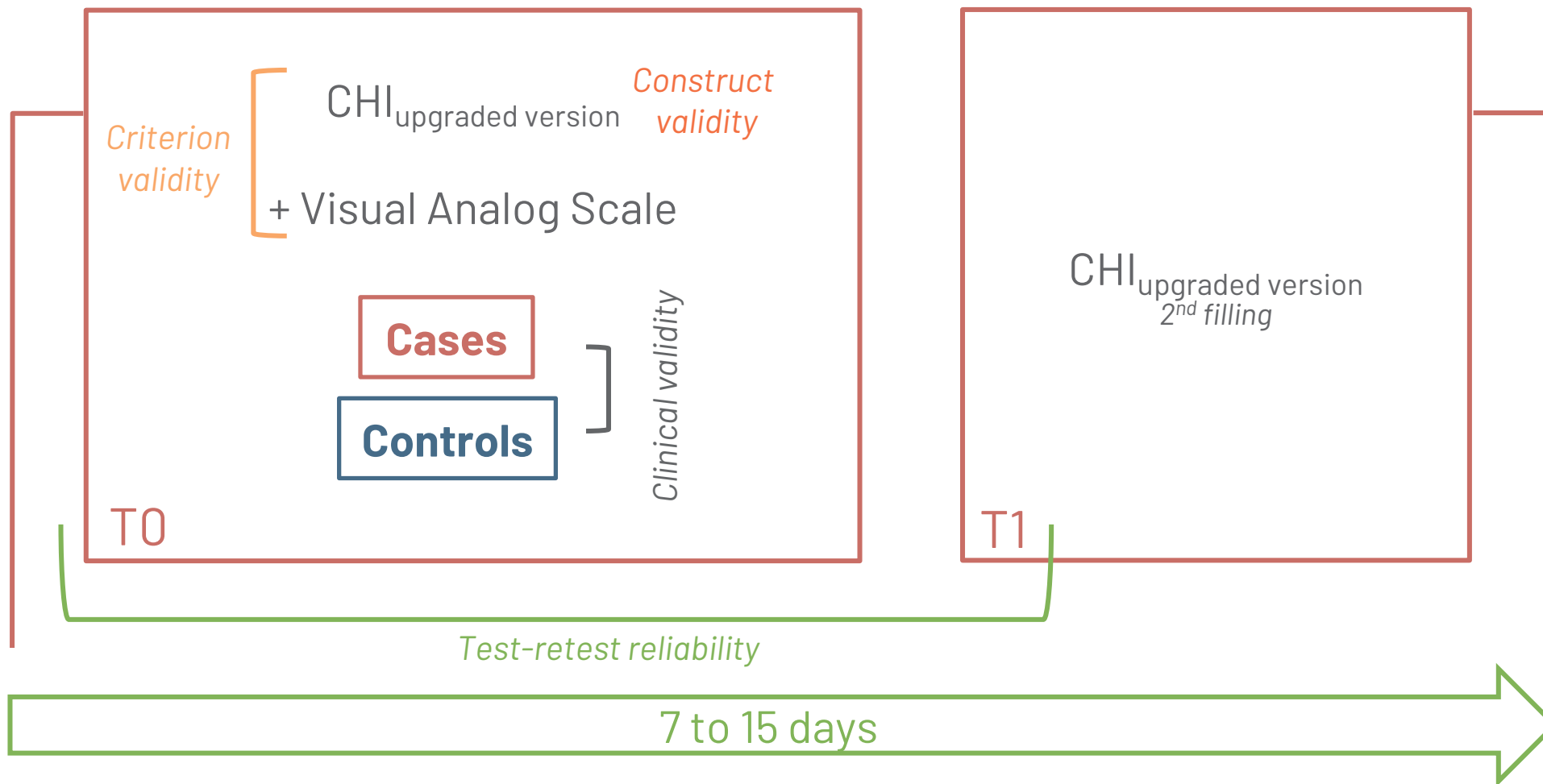
Veuillez mettre une croix dans la case qui correspond à votre situation actuelle, en sachant que :

J= jamais PJ=presque jamais P= parfois PT=presque toujours T= toujours

		J	PJ	P	PT	T
DL1	Prenez-vous des médicaments pour la douleur ?					
DL2	Vous réveillez-vous la nuit à cause des douleurs ?					
DL3	Êtes-vous gêné dans vos activités à cause des douleurs ?					
DL4	Présentez-vous des crises de douleur ?					
DL						
DG1	Ressentez-vous une gêne pour avaler ?					
DG2	Vous arrive-t-il de vous étouffer en mangeant ou en buvant ?					
DG3	Sentez-vous des remontées de liquide ou d'aliments après le repas ?					
DG4	Avez-vous des difficultés à mâcher ?					
DG						
N1	Êtes-vous obligé de modifier la consistance des aliments pour pouvoir avaler ?					
N2	La durée du repas est-elle augmentée à cause de vos difficultés pour avaler ?					
N3	Avez-vous besoin d'enrichir votre alimentation ?					
N4	Perdez-vous du poids ?					
N						
R1	Êtes-vous gêné pour respirer au repos ?					
R2	Vos difficultés respiratoires limitent-elles vos activités physiques ?					
R3	Vous sentez-vous encombré ?					
R4	Avez-vous besoin de dormir en position demi-assise ?					
R						
PH1	Avez-vous des difficultés pour parler ?					
PH2	Votre entourage a-t-il des difficultés pour vous comprendre ?					
PH3	Parlez-vous moins souvent avec votre famille, vos amis, vos voisins ?					
PH4	Avez-vous des difficultés pour articuler ?					
PH						
A1	Faites-vous répéter quand on vous parle ?					
A2	Avez-vous du mal à suivre les conversations en milieu bruyant ?					
A3	Êtes-vous gêné pour comprendre les conversations au téléphone ?					
A4	Avez-vous des bruits dans les oreilles ?					
A						
V1	Êtes-vous gêné pour voir dans la pénombre ?					
V2	Avez-vous l'impression de voir moins bien de loin ou de près ?					
V3	Êtes-vous gêné par des éblouissements ou des « papillons » devant les yeux ?					
V4	Présentez-vous une diminution de votre champ de vision ?					
V						
OG1	Êtes-vous gêné pour sentir les odeurs ?					
OG2	Avez-vous peur d'un accident à cause de vos problèmes d'odorat ?					
OG3	Êtes-vous gêné pour percevoir le goût des aliments ?					
OG4	Vous sentez-vous frustré à cause de vos problèmes de goût ou d'odorat ?					
OG						
C1	Êtes-vous gêné par les changements de votre aspect physique ?					
C2	Êtes-vous gêné par la manière dont les autres vous regardent depuis votre maladie ?					
C3	Les changements de votre aspect physique limitent-ils votre vie sociale ?					
C4	Les conséquences de votre maladie modifient-elles votre vie intime ?					
C						
E1	Avez-vous une modification de sensibilité au niveau du cou, des épaules et/ou des bras ?					
E2	Avez-vous des difficultés pour tourner la tête ?					
E3	Avez-vous des difficultés pour porter du poids ?					
E4	Êtes-vous limité pour lever les bras ?					
E						
PS1	Votre vie personnelle et sociale est-elle limitée par les problèmes liés à votre maladie ?					
PS2	Votre maladie a-t-elle modifiée vos rapports avec autrui ?					
PS3	Êtes-vous contrarié par les problèmes liés à votre maladie ?					
PS4	Vous sentez-vous handicapé à cause des suites de votre maladie ?					
PS						
TOTAL						

Y a-t-il autre chose qui vous gêne ?


# Materials and Methods



# Materials and Methods

Analysis of priority dimensions to be supported:


Hierarchical ranking by the patient  
of all the dimensions in order of importance (ICC)



Categorization of each patient's top-3 priorities



Performance evaluation of the top-3 priority  
dimensions:  
Sensitivity, Specificity, Area Under the Curve



Determination of the best threshold  
starting from which the dimension is in the top 3  
of the patient's priorities



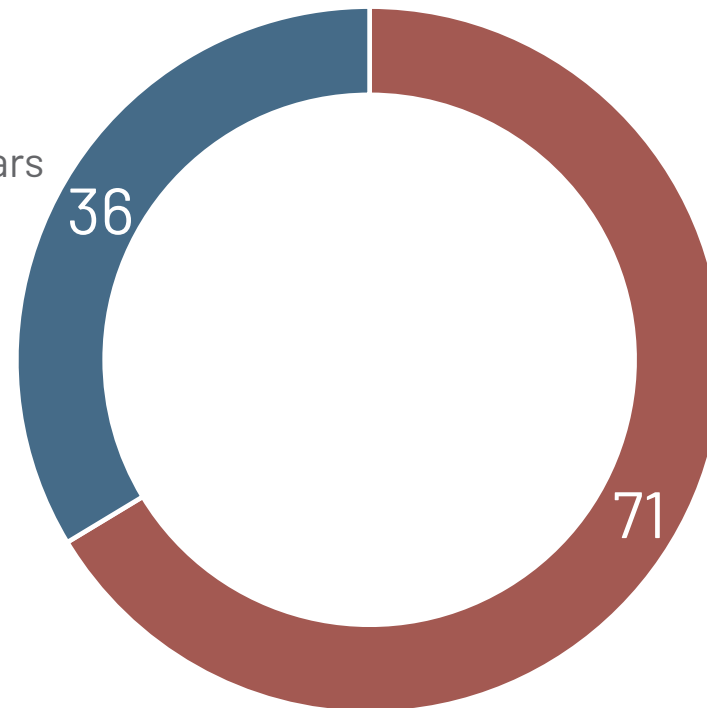
# Results

## Cases and controls: descriptive data

### Controls

17 M, 19 F

Mean age 59.5 years



### Cases

46 M, 25 F

Mean age 64.6 years

*Tumor locations:*

*Oral cavity: 19.7%*

*Larynx: 21.1%*

*Pharynx: 29.6%*

*Other location: 29.6%*

# Results

Psychometric properties of the 2 new dimensions:

		Limitation of neck and shoulder movements	Psychosocial impact of changes in the physical appearance
Validity	<b>Construct validity (convergent validity)</b>	$r_{\text{Spearman}}: .38 - .73$	$r_{\text{Spearman}}: .35 - .61$
	<b>Clinical validity</b>	Mann-Whitney U test: $p < .001$	Mann-Whitney U test: $p < .001$
	<b>Criterion validity</b>	$r_{\text{Spearman}} = .68 (p < .001)$	$r_{\text{Spearman}} = .74 (p < .001)$
Reliability	<b>Internal consistency</b>	Cronbach's alphas $> .72$	Cronbach's alphas $> .75$
	<b>Test-retest reliability (response rate: 63%)</b>	$r_{\text{Spearman}} = .80 (p < .001)$	$r_{\text{Spearman}} = .67 (p < .001)$

# Results

Determination of the top-3 threshold:

Dimensions	AUC (Area Under the Curve)	CI 95 %	Threshold			
			Chosen threshold	Sensitivity	Specificity	Correct classification
Pain	.73	[.58 ; .87]	<b>7</b>	64.7%	73.6%	71.4%
Swallowing	.84	[.73 ; .94]	<b>4</b>	93.6%	56.5%	81.4%
Feeding	.78	[.67 ; .89]	<b>7</b>	80.8%	72.7%	75.7%
Respiration	.74	[.54 ; .94]	<b>4</b>	87.5%	50.0%	54.3%
Phonation	.85	[.74 ; .95]	<b>6</b>	90.9%	65.4%	81.4%
Hearing	.88	[.79 ; .96]	<b>8</b>	83.3%	81.0%	81.4%
Vision	.55	[.35 ; .75]	<b>NC</b>	NC	NC	NC
Olfaction-Gustation	.86	[.69 ; 1.00]	<b>7</b>	77.8%	85.3%	84.3%
Psychosocial impact of changes in the physical appearance	.68	[.49 ; .88]	<b>NC</b>	NC	NC	NC
Neck and/or shoulder limitations	.70	[.57 ; .83]	<b>7</b>	70.8%	52.2%	58.6%
Psychosocial	.48	[.21 ; .75]	<b>NC</b>	NC	NC	NC

# Discussion

Acceptable psychometric properties:

Construct validity	Clinical validity	Criterion validity	Internal consistency	Test-retest reliability
<ul style="list-style-type: none"><li>• 11-dimension structure validated</li><li>• Moderate correlation between Swallowing and Feeding</li><li>• Impact of psychosocial dimension on other scores?</li></ul>	<ul style="list-style-type: none"><li>• Pain and Vision: weak</li></ul>	<ul style="list-style-type: none"><li>• Good correlations between CHI scores and VAS</li></ul>	<ul style="list-style-type: none"><li>• High Cronbach's alphas &gt; .72</li></ul>	<ul style="list-style-type: none"><li>• Good correlations between T0 and T1 (<math>r &gt; .67</math>): reproducible measure</li></ul>

# Discussion

Clinical use:

Modular application

Threshold:

No threshold for 3 dimensions

Cautious interpretation  
for 3 other dimensions

Acceptable performance  
(> 75%) for the other dimensions

CHI: valid and reliable tool

Dimension	AUC (Area Under the Curve)	Threshold	
		Chosen threshold	Correct classification
Pain	.73 [.58 ; .87]	7	71.4%
Swallowing	.84 [.73 ; .94]	4	81.4%
Feeding	.78 [.67 ; .89]	7	75.7%
Respiration	.74 [.54 ; .94]	4	54.3%
Phonation	.85 [.74 ; .95]	6	81.4%
Hearing	.88 [.79 ; .96]	8	81.4%
Vision	.55 [.35 ; .75]	ND	ND
Olfaction-Gustation	.86 [.69 ; 1.00]	7	84.3%
Psychosocial impact of changes in the physical appearance	.68 [.49 ; .88]	ND	ND
Neck and/or shoulder limitations	.70 [.57 ; .83]	7	58.6%
Psychosocial	.48 [.21 ; .75]	ND	ND