Dutch translation and validation of the Communicative Participation Item Bank (CPIB)-short form


DOI
10.1111/1460-6984.12775

Publication date
2023

Document Version
Final published version

Published in
International Journal of Language and Communication Disorders

License
CC BY-NC-ND

Citation for published version (APA):

General rights
It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations
If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: https://uba.uva.nl/en/contact, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.

UvA-DARE is a service provided by the library of the University of Amsterdam (https://dare.uva.nl)
Dutch translation and validation of the Communicative Participation Item Bank (CPIB)—short form

Klaske E. van Sluis¹,² | Ellen Passchier¹,² | Rob J. J. H. van Son¹,² | Lisette van der Molen¹,² | Martijn Stuiver¹,³,⁴ | Michiel W. M. van den Brekel¹,² | Leen Van den Steen⁵,⁶ | Johanna G. Kalf⁷ | Gwen van Nuffelen⁵,⁶,⁸

¹Department of Head and Neck Oncology and Surgery, Netherlands Cancer Institute-Antoni van Leeuwenhoek, Amsterdam, the Netherlands  
²Amsterdam Center for Language and Communication, University of Amsterdam, Amsterdam, the Netherlands  
³Center for Quality of Life and Division of Psychosocial Research and Epidemiology, Netherlands Cancer Institute, Amsterdam, the Netherlands  
⁴Center of Expertise Urban Vitality, Faculty of Health, Amsterdam University of Applied Sciences, Amsterdam, the Netherlands  
⁵Department of Otolaryngology and Head and Neck Surgery—Rehabilitation Center for Communication Disorders, Antwerp University Hospital, Antwerp, Belgium  
⁶Faculty of Medicine and Health Sciences, University of Antwerp, Antwerp, Belgium  
⁷Department of Rehabilitation, Radboud University Medical Center, Donders Institute for Brain, Cognition and Behaviour, Nijmegen, the Netherlands  
⁸Department of Speech, Language and Hearing Sciences, Faculty of Medicine and Health Sciences, University of Ghent, Ghent, Belgium

Abstract

Background: Several conditions and diseases can result in speech problems that can have a negative impact on everyday functioning, referred to as communicative participation. Subjective problems with acquired speech problems are often assessed with the speech handicap index (SHI). To assess generic participation problems, the Utrecht Scale for Evaluation of Rehabilitation—Participation (USER-P) questionnaire is frequently used. The English questionnaire Communicative Participation Item Bank—short form (CPIB short form) is a 10-item valid, reliable instrument that assesses communicative participation. In the absence of a Dutch equivalent, translation and validation of the CPIB short form was required.

Aims: To translate the CPIB short form into Dutch, and to determine its psychometric properties for the group of adults with speech problems resulting from a neurological aetiology or head and neck cancer.

Methods & Procedures: Translation of the CPIB short form was performed following the instructions of the European Organisation for Research and Treatment for Cancer (EORTC). In a cross-sectional multi-centre study, participants completed the Dutch CPIB short form together with the SHI and USER-P, and the CPIB a second time after 2 weeks. We assessed internal consistency and test-retest reliability of the CPIB. Construct validity was assessed based on correlations with SHI, USER-P and speech assessments.

Outcomes & Results: In the validation study, 122 participants were included: 51 with dysarthria due to different neurological disorders, 48 with speech problems due to head and neck cancer treatment and 23 healthy controls. Internal consistency of the items was high (Cronbach’s alpha = 0.962), the intraclass correlation coefficient (ICC) for test-retest reliability was high 0.908 (95% CI = 0.870–0.935). Construct validity was supported by a strong correlation between...
the Dutch CPIB short form and the SHI total score (SHI total $r_s = 0.887$) and a moderate correlation between the Dutch CPIB-10 and the USER-P subscales (USER-P Frequency $r_s = 0.365$; USER-P restrictions and USER-P satisfaction $r_s = 0.546$). A moderate correlation was found between the Dutch CPIB-10 and the speech performance assessments (degree of distortedness $r = -0.0557$; $p \leq 0.001$; degree of intelligibility $r = 0.0562$).

**Conclusions & Implications:** The Dutch CPIB short form provides a valid and reliable tool for clinical practice and research purposes. It allows clinicians to start using this PROM in clinical and research practice to systematically investigate the impact of the speech problems on communicative participation in a Dutch-speaking population.

**KEYWORDS**
communicative participation, dysarthria, patient-reported outcome, speech disorder

**What this paper adds**
*What is already known on the subject*
- Communicative participation allows people to take part in life situations, but can be affected by acquired speech problems. The CPIB is a patient-reported outcome measure for the assessment of this concept. For the English language the 46-item bank and a 10-item short form is available.

*What this paper adds to existing knowledge*
- This paper describes the process of translation of the CPIB short form into Dutch, and confirms its reproducibility and validity.

*What are the potential or actual clinical implications of this work?*
- With this validated Dutch version of the CPIB short form available, professionals can implement this tool in clinical and research practice to systematically evaluate communicative participation.

**INTRODUCTION**

Health is defined by the World Health Organization (WHO) as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (WHO, 1948). To classify health outcomes the WHO’s International Classification of Functioning Disability and Health (ICF) (2001) provides a framework for interaction of altered body structures or functions, activity and participation related to health condition within the context of personal and environmental factors. In this classification, participation is defined as ‘involvement in a life situation’ and concerns multiple domains, for example, mobility, social interactions, self-care, learning and communication. Communicative participation is defined as ‘taking part in life situations where knowledge, information, ideas, and feelings are exchanged’ (Eadie et al., 2006).

Patient-reported outcome measures (PROMs) are used to measure the patients’ perceptions of their symptoms, their functional status and their health-related quality of life (Black, 2013). PROMs have an important role in the transition to patient-centred healthcare. There is also a growing interest in speech language therapy and rehabilitation practice to include PROMs in clinical practice.

Problems with verbal speech, such as altered voice or speech disorders, can have a negative impact on communicative participation. To quantify experienced physical impairments, limitation in activities and social participation related to voice and speech disorders several PROMs exist. The voice handicap index (VHI) (Jacobson et al.,
the VHI 10-item version (VHI-10) (Rosen et al., 2004), the speech handicap index (SHI) 15-item version (Van den Steen et al., 2011), and the SHI 30-item version (Rinkel et al., 2008) are validated and commonly used PROMs for speech and voice-related disorders within Dutch.

However, the SHI and VHI do not specifically aim to measure communicative participation. The VHI and SHI measure impairment, function, and activity problems together, which limits the bandwidth for coverage of communicative participation. To assess problems with participation, the validated Utrecht Scale for Evaluation of Rehabilitation–Participation (USER-P) is most often used to assess participation in rehabilitation practice in the Netherlands (Post et al., 2012). The USER-P is a generic participation instrument measuring both objective and subjective participation in adults. Objective questions about the frequency of activities are included as well as subjective ratings of, for example, satisfaction with these activities. However, its focus is on functional mobility and occupational performance and less on activities associated with communication.

The CPIB developed by Baylor et al. (2013) is a PROM for the measurement of communicative participation in everyday speaking situations (Baylor et al., 2013). This PROM was developed to assess self-reported restrictions in communicative participation across different communication disorders in community-dwelling adults (Baylor et al., 2011). The CPIB includes a 46-item questionnaire which was developed with item response theory (IRT) and can be used for different diagnosis groups (Baylor et al., 2013). The full item bank was reduced into a 10-item disorder generic short form, for which items were selected on the basis of a combination of statistical analyses and judgment by the speech and language practitioner (SLP). Reliability between the full 46-item set and the 10-item short form appeared adequate (Baylor et al., 2013).

The development of the original CPIB (short form) was performed in patients with medical conditions often associated with communication disorders. Acquired speech disorders can be subclassified into disorders that have a structural aetiology or a neurological nature (Cummings, 2013). Many speech disorders can result from several neurological diseases, for example, Parkinson’s disease, multiple sclerosis or dysarthria as a consequence of stroke (Cummings, 2013). Head and neck cancer can cause speech disorders with a structural (e.g., patients who underwent a partial glossectomy) or neurological aetiology (e.g., polyneuropathy post-radiotherapy).

In a recent review by the original authors, the use of the CPIB and CPIB short form is described for different diagnostic groups such as people with neurological speech and language disorders, aphasia, degenerative diseases, head and neck cancer, and voice disorders (Baylor et al., 2021). Psychometric properties within the English-speaking population were investigated and proved to be adequate (Baylor et al., 2021). To date, no validated translations of the CPIB and/or CPIB short form are available. Having the CPIB available in a broader range of languages can help to implement this PROM in international clinical and research practice. We achieved cross-cultural usability validation of the CPIB short form into Dutch: Dutch is spoken in both the Netherlands and Belgium. In the northern part of Belgium, a dialect cluster of Dutch is spoken, referred to as Flemish Dutch. In this paper, both language areas are included when we refer to Dutch. One of the goals of the study was to achieve a cross-cultural usability of the Dutch CPIB short form for both language areas.

This study aims to produce a translation the CPIB short form into Dutch and to determine its psychometric properties (construct validity and reliability) in a population of Dutch-speaking adults with speech problems caused by neurological aetiology or head and neck cancer.

**METHODS**

**Translation procedures**

After permission from the original authors, translation of the CPIB short form was performed following the instructions of the European Organisation for Research and Treatment of Cancer (EORTC) (Koller et al., 2007) and the Consensus-based Standards for the selection of health MeasurementInstruments (COSMIN) regulations (Terwee et al., 2018). Language variation between Dutch and Flemish Dutch has been taken into account with the objective of obtaining a single translation suitable for both language areas. The following steps were taken during translation: (1) Forward translation. (2) Reviewing: expert panel meeting to establish consensus forward translation in Dutch. The expert panel consisted of health care professionals, a methodologist and a linguist. Issues in language variation between Dutch and Flemish Dutch were discussed until consensus was reached. (3) Back-translation. (4) Reviewing and comparison: expert panel meeting to create consensus on the back-translation, comparison of the back-translated version and the original version by members of the research team. (5) Pilot-testing and cognitive interviewing including the assessment of face validity. In total, 22 patients, 10 Dutch and 12 Belgian, were asked whether the Dutch CPIB short form was understandable. They were requested to score clarity of items, if items were disturbing (yes/no), and if they had any comments. These patients varied with regard to pathology, severity of speech disorder, age, social economic and educational
The speakers sound... (VAS score from ‘very distorted’ 2019 to 2011, 2014, 2017 to 2010, 1968 < 2010)

Validity of the Dutch CPIB short form, outcome measure-less interference in participation. To assess the construct, sum scores range from 0 to 30, higher scores indicate more interference.

Participants included in the study. Ten informed consent was obtained from all individual participants. Written informed consent was obtained from all individual participants. Written informed consent was obtained from all participating centres. Written informed consent was obtained from all individual participants included in the study.

Procedure and measurements

This cross-sectional multicentre study was conducted according to the ethical guidelines of the Declaration of Helsinki (Association, 2013). The study was approved by the Institutional Review Board of the Netherlands Cancer Institute and accepted by all participating centres. Written informed consent was obtained from all individual participants included in the study.

The Dutch CPIB short form (see Appendix A) has 10 items from which a raw score is calculated by summation of the point values corresponding for the extent of interference reported for each item (‘Not at all’ = 3 points; ‘A little’ = 2 points; ‘Quite a bit’ = 1 point; ‘Very much’ = 0 points). Sum scores range from 0 to 30, higher scores indicate less interference in participation. To assess the construct validity of the Dutch CPIB short form, outcome measures targeting speech and participation were obtained. The following PROMs were used: speech handicap index (SHI) (Van den Steen et al., 2011), Utrecht Scale for Evaluation of Rehabilitation—Participation (USER-P) (Post et al., 2012), and Nederlandstalig Dysarthrieonderzoek volwassenen (Dutch Dysarthria assessment—NDO-V) (Knuijt et al., 2014). The SHI contains 16 items and covers three subscales to measure emotional, functional and physical components. The USER-P is a generic participation instrument that measures both objective and subjective participation in adults with 31 items in three scales: Frequency, Restrictions and Satisfaction.

Participants were recruited at two Dutch hospitals: The Netherlands Cancer Institute, Amsterdam, and Radboud University Medical Center, Nijmegen; and at four Belgian institutes: University Hospital Antwerp, University Hospital Gent, Multiple Sclerosis Center Over pelt and Academic Hospital Sint-Jan, Bruges. Participants were identified and approached by the researchers and speech-language therapists. Sample size estimation followed the pragmatic criteria set-up for validation studies by the Dutch Institute for Health and Research (EMGO), which state that a sample size of at least 50 per neurological and head and neck cancer group is needed. To compare scores with healthy controls, at least 20 healthy participants were recruited.

Study assessments were carried out at two study time points, further referred to as T1 and T2 (2 weeks after T1). At T1, participants completed the Dutch CPIB short form, the SHI and USER-P questionnaires in the presence of the researcher. Additionally, cognitive functioning was assessed with the Montreal Cognitive Assessment (MOCA) to determine if cognitive problems (MOCA < 26), lead to deviating scores on the Dutch CPIB short form (Nasreddine et al., 2005). Next to this, speech recordings were made.

At T2, the participants completed the Dutch CPIB short form at home and returned it by mail. During both assessments the participant was instructed to fill out the PROMs by themselves on paper. No explicit help of the researcher or relatives was allowed.

Listening experiment

To evaluate intelligibility and distortedness of the speech, a listening experiment was conducted. These speech performance measures consisted of a perceptual assessment of the severity of the speech disorder, which is still considered as the gold standard (Duffy, 1968; Dwivedi et al., 2012). Speech recordings were made with the semi-structured interview from the NDO-V (Knuijt et al., 2014, 2017; Martens et al., 2010). For each speaker a fragment of 10 s was cut-out. A listening experiment was performed by nine senior speech languages therapy students from the Netherlands. The listeners were instructed not to judge the dialect differences between Dutch and Flemish Dutch speech. There were 111 samples that were divided in three random lists of 37 samples which were presented to the listeners. Each fragment was independently rated by three listeners. The samples were rated on a computer screen version of the visual analogue scales (VAS). Listeners had to answer two questions for each fragment:

- The speaker sounds ... (VAS score from ‘very distorted’ to ‘not distorted at all’, score 0–1000).
• The speaker is ... (VAS score from ‘very unintelligible’ to ‘completely intelligible’).

**Analysis**

All digitalized data were stored in a secured electronic data capture system (Castor, 2019). Statistical analyses were performed in SPSS version 27.0 (IBM, 2020); the results of the listening experiment were analysed in R (Team, 2020).

**Statistical analysis**

Descriptive summary statistics for the scale were calculated for each group, and for the total sample.

Likewise, internal consistency was estimated with the Cronbach’s alpha coefficient, accepting values between 0.70 and 0.95 (Terwee et al., 2007). Test–retest reliability, indicating that the questionnaire measures the same outcome within the same person under the same conditions, was determined using an intraclass correlation coefficient (ICC; two-way mixed-effect model based on single measures and consistency type) and reported with a 95% confidence interval. An ICC > 0.70 was considered acceptable (Terwee et al., 2018). Acceptable floor and ceiling effects were defined as less than 15% minimum and maximum scores on a scale (Terwee et al., 2007).

Construct validity was tested by evaluating a number of hypotheses. Sum scores of the Dutch CPIB short form were correlated with the total scores and subscales of the SHI and USER-P, using Spearman’s rank correlation coefficient ($r_s$). We hypothesized: (1) a strong correlation of $r_s > 0.70$ with the total score and subscales of the SHI; (2) a moderate (correlation $r_s = 0.30–0.70$) with the USER-P satisfaction and restrictions subscales; and (3) a weak correlation ($r_s < 0.30$) with the USER-P frequency subscale. Furthermore, known groups validation was performed, hypothesizing that participants with neurological or head and neck cancer speech disorders would have statistically significant worse scores on the Dutch CPIB short form compared with healthy controls.

**Analysis listening experiment**

Inter-listener reliability was checked with multiple ICC2K (Revelle, 2017). Pearson’s correlation was used to correlate outcomes of the listening experiment with outcomes on the Dutch CPIB short form. We hypothesized a moderate correlation ($r = 0.30–0.70$) between the perceptual scales (degree of distortedness and degree of intelligibility) and the Dutch CPIB short form outcomes.

**RESULTS**

**Outcomes translation procedures**

There were several remarks from the 22 patients who were involved in the process of pilot testing. They suggested concepts that could be added, such as the ability to use the telephone. Participants stated that, to them, some items were not applicable, such as talking in a group. They judged all items as understandable although some items were confronting. With the Dutch translation of the CPIB short form pilot testing was performed, several issues were revealed, as shown in Appendix A. These issues were discussed within the research team but did not lead to adaptations. Appendix B shows the full list of comments of the participants, as recommended by the COSMIN regulations (Terwee et al., 2018).

**Outcomes validation procedures**

In the validation study, 122 participants were included, of whom 51 with dysarthria, 48 with speech problems due to head and neck cancer treatment and 23 healthy controls. Table 1 shows the demographic information of the participants; conditions of the aetiological subgroups are also presented. For the neurological participants, Parkinson’s disease was the most frequent aetiology (31%), for the head and neck cancer group of participants the cancer most frequently originated from the oral cavity (53%) and the larynx (27%). Median time since diagnosis was 6 years for the neurological group and 1.5 years for the head and neck cancer group. Cognitive functioning indicated mild cognitive impairment (MOCA < 26) was present in 47% of the group of neurological disorders, 52% of the head and neck cancer group and 22% of the healthy controls. Prior speech pathology service had been received by 61% of the neurological participants and 85% of the head and neck cancer participants. T1 assessment was carried out in all 122 participants, T2 assessments were returned by 117 participants (96%).

Cronbach’s alpha was 0.95, indicating an excellent internal consistency reliability, with no items showing evidence of harming the internal consistency reliability.

The overall ICC for test–retest reliability of the Dutch CPIB short form was 0.91 (95% CI = 0.87–0.93), indicating excellent reproducibility. In participants with a MOCA < 26, the ICC was 0.86 (95% CI = 0.76–0.92), in participants with a MOCA > 26 the ICC was 0.94 (95% CI = 0.90–0.96). In the neurological group an ICC of 0.78 (95% CI = 0.65–0.87) was found, for the head and neck cancer group an
TABLE 1 Demographic information of participants (n = 122)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Category</th>
<th>Neuro (n = 51)</th>
<th>HNC (n = 48)</th>
<th>Healthy (n = 23)</th>
<th>Total (n = 122)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aetiology, n (%)</td>
<td>Parkinson’s disease</td>
<td>16 (31)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>CVA</td>
<td>6 (12)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Myotonic dystrophy</td>
<td>9 (18)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>ALS</td>
<td>5 (9)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>MS</td>
<td>2 (4)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Oral cavity cancer</td>
<td></td>
<td>25 (53)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Larynx cancer</td>
<td></td>
<td>13 (27)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Oropharynx cancer</td>
<td></td>
<td>4 (8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hypopharynx cancer</td>
<td></td>
<td>2 (4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other/unknown</td>
<td>13 (26)</td>
<td>4 (8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age, years, mean (SD)</td>
<td></td>
<td>58 (14.6)</td>
<td>66 (10.4)</td>
<td>53 (20.4)</td>
<td>61 (15.2)</td>
</tr>
<tr>
<td>Sex, n (%)</td>
<td>Men</td>
<td>35 (69)</td>
<td>34 (71)</td>
<td>8 (35)</td>
<td>77 (63)</td>
</tr>
<tr>
<td></td>
<td>Women</td>
<td>16 (31)</td>
<td>14 (29)</td>
<td>15 (65)</td>
<td>45 (37)</td>
</tr>
<tr>
<td>Partner, n (%)</td>
<td>Yes</td>
<td>41 (80)</td>
<td>32 (67)</td>
<td>16 (70)</td>
<td>89 (73)</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>10 (20)</td>
<td>16 (33)</td>
<td>7 (30)</td>
<td>33 (27)</td>
</tr>
<tr>
<td>Region, n (%)</td>
<td>The Netherlands</td>
<td>8 (16)</td>
<td>47 (98)</td>
<td>8 (35)</td>
<td>63 (52)</td>
</tr>
<tr>
<td></td>
<td>Belgium, Flanders</td>
<td>43 (84)</td>
<td>1 (2)</td>
<td>15 (65)</td>
<td>59 (48)</td>
</tr>
<tr>
<td>Living situation, n (%)</td>
<td>Alone</td>
<td>8 (16)</td>
<td>16 (33)</td>
<td>4 (17)</td>
<td>28 (23)</td>
</tr>
<tr>
<td></td>
<td>Together</td>
<td>43 (84)</td>
<td>32 (67)</td>
<td>19 (83)</td>
<td>94 (77)</td>
</tr>
<tr>
<td>Education, n (%)</td>
<td>≤12 years of education</td>
<td>22 (43)</td>
<td>22 (46)</td>
<td>6 (26)</td>
<td>50 (41)</td>
</tr>
<tr>
<td></td>
<td>&gt;12 years of education</td>
<td>29 (57)</td>
<td>26 (54)</td>
<td>17 (74)</td>
<td>72 (59)</td>
</tr>
<tr>
<td>Employment status, n (%)</td>
<td>Paid work</td>
<td>10 (20)</td>
<td>10 (21)</td>
<td>13 (57)</td>
<td>33 (27)</td>
</tr>
<tr>
<td></td>
<td>Self-employed</td>
<td>2 (4)</td>
<td>4 (8)</td>
<td>2 (9)</td>
<td>8 (7)</td>
</tr>
<tr>
<td>Multiple options possible</td>
<td>Unpaid work/volunteering</td>
<td>4 (8)</td>
<td>3 (6)</td>
<td>2 (9)</td>
<td>9 (7)</td>
</tr>
<tr>
<td></td>
<td>Studying</td>
<td>1 (2)</td>
<td>0 (0)</td>
<td>3 (13)</td>
<td>4 (3)</td>
</tr>
<tr>
<td></td>
<td>Pension</td>
<td>20 (39)</td>
<td>29 (60)</td>
<td>7 (30)</td>
<td>56 (46)</td>
</tr>
<tr>
<td></td>
<td>Unemployed</td>
<td>1 (2)</td>
<td>1 (2)</td>
<td>0 (0)</td>
<td>2 (2)</td>
</tr>
<tr>
<td></td>
<td>Disability pension</td>
<td>19 (37)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>19 (16)</td>
</tr>
<tr>
<td></td>
<td>Sick leave</td>
<td>6 (12)</td>
<td>5 (10)</td>
<td>0 (0)</td>
<td>11 (9)</td>
</tr>
<tr>
<td></td>
<td>Housekeeping</td>
<td>4 (8)</td>
<td>6 (13)</td>
<td>0 (0)</td>
<td>10 (8)</td>
</tr>
<tr>
<td>Time since diagnosis, years, median (range)</td>
<td>6 (3–35)</td>
<td>1.5 (0–36)</td>
<td>–</td>
<td>–</td>
<td></td>
</tr>
<tr>
<td>MOCA score, n (%)</td>
<td>≥ 26</td>
<td>27 (53)</td>
<td>23 (48)</td>
<td>18 (78)</td>
<td>68 (58)</td>
</tr>
<tr>
<td></td>
<td>&lt; 26</td>
<td>24 (47)</td>
<td>25 (52)</td>
<td>5 (22)</td>
<td>54 (44)</td>
</tr>
<tr>
<td>History of hearing loss, n (%)</td>
<td>Presence of hearing loss</td>
<td>8 (16)</td>
<td>20 (42)</td>
<td>8 (35)</td>
<td>36 (30)</td>
</tr>
<tr>
<td>Prior speech pathology services n (%)</td>
<td>Had prior speech pathology services</td>
<td>31 (61)</td>
<td>41 (85)</td>
<td>3 (13)</td>
<td>–</td>
</tr>
</tbody>
</table>

Note: HNC, head and neck cancer; MS, multiple sclerosis; Neuro, neurological aetiology; CVA, cerebro vasculair accident; ALS, amyotrophic lateral sclerosis.

ICC of 0.92 (95% CI = 0.86–0.96) was found, for the healthy participants an ICC of 0.99 (95% CI = 0.98–0.99) was found.

Table 2 reports the range of study outcomes and floor and ceiling effects. All study outcomes had an approximately normal distribution. Median and mean scores are displayed with interquartile range (IQR) and standard deviations (SD) in Table 2. Mean scores on the Dutch CPIB short form were 14.0 (SD = 8) for the neurological group, 20.2 (SD = 8) for the head and neck cancer group and 28.0 (SD = 6) for the healthy controls. A ceiling effect of 74% was seen for the healthy controls at both T1 and T2 assessment. For the head and neck cancer group at T2 a ceiling effect was seen, with 23% achieving the maximum, indicating no communicative participation problems. Scores of the Dutch CPIB short form per group are visualised in Figure 1.

As hypothesized, we found a strong correlation between the Dutch CPIB short form and the SHI total score ($r_s = 0.887$) and subscales (SHI Physical $r_s = 0.830$; SHI Emotional $r_s = 0.850$; SHI Functional $r_s = 0.829$). Also as
### TABLE 2 Outcomes study measures

<table>
<thead>
<tr>
<th>Variable, scale range</th>
<th>Neuro (n = 51)</th>
<th>HNC (n = 48)</th>
<th>Healthy (n = 23)</th>
<th>Total (n = 122)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Median (IQR)</td>
<td>Range</td>
<td>% floor–% ceiling</td>
</tr>
<tr>
<td>Dutch CPIB short form (0–30), T1</td>
<td>14 (8)</td>
<td>13 (14)</td>
<td>0–30</td>
<td>2–2</td>
</tr>
<tr>
<td>SHI total score (0–60)$^a$</td>
<td>28.6 (10)</td>
<td>31 (19)</td>
<td>10–47</td>
<td>0–0</td>
</tr>
<tr>
<td>SHI physical (0–20)$^a$</td>
<td>12 (4.2)</td>
<td>12 (6)</td>
<td>2–20</td>
<td>0–4</td>
</tr>
<tr>
<td>SHI emotional (0–20)$^a$</td>
<td>9 (4.5)</td>
<td>10 (6)</td>
<td>0–16</td>
<td>4–6</td>
</tr>
<tr>
<td>SHI functional (0–20)$^a$</td>
<td>8 (3.3)</td>
<td>8 (5)</td>
<td>1–13</td>
<td>0–0</td>
</tr>
<tr>
<td>USER-P frequency (0–100)</td>
<td>33 (14)</td>
<td>31 (21.6)</td>
<td>10–65</td>
<td>0–0</td>
</tr>
<tr>
<td>USER-P restrictions (0–100)</td>
<td>66 (21)</td>
<td>64 (35.2)</td>
<td>17–97</td>
<td>0–0</td>
</tr>
<tr>
<td>USER-P satisfaction (0–100)</td>
<td>67 (14)</td>
<td>67 (20.5)</td>
<td>22.2–93</td>
<td>0–0</td>
</tr>
<tr>
<td>Listening-experiment distortedness (0–1000)</td>
<td>435 (283)</td>
<td>344 (244)</td>
<td>1–964</td>
<td>0–0</td>
</tr>
<tr>
<td>Listening-experiment intelligibility (0–1000)</td>
<td>406 (281)</td>
<td>406 (281)</td>
<td>1–909</td>
<td>0–0</td>
</tr>
</tbody>
</table>

Note: $^a$ Higher score indicates worse functioning.

Dutch CPIB short form Dutch, Dutch Communicative Participation Item Bank—short form; HNC, head and neck cancer; MOCA, Montreal cognitive assessment; Neuro, neurological aetiology; SHI, speech handicap index; USER-P, Utrecht Scale for Evaluation of Rehabilitation–Participation.
hypothesized, we found a moderate correlation between the Dutch CPIB short form and the USER-P restrictions ($r_s = 0.660$) and the USER-P satisfaction ($r_s = 0.546$). A moderate instead of a weak correlation was found for the USER-P Frequency scale ($r_s = 0.365$). Thus, two out of the three hypotheses were confirmed in absolute numbers, while the order of magnitude of correlations was consistent with all a priori assumptions. Correlations between all scales and subscales are presented in Table 3.
Mann–Whitney U-testing showed a statistically significant difference between participants with speech disorders compared to healthy controls, as well as between groups with different aetiologies.

**Listening experiment**

The listening experiment was performed on 111 study participants because due to an administrative error, speech recordings from 12 participants were missing.

The inter-listener reliability was high, with an ICC2K of 0.800 for degree of intelligibility and 0.744 for degree of distortedness. Pearson’s correlation showed a statistically significant moderate correlation between the outcomes on the Dutch CPIB short form at T1 and the listening experiment: degree of distortedness $r = -0.0557; p \leq 0.001$; degree of intelligibility $r = 0.0562; p \leq 0.001$; confirming the hypotheses.

**DISCUSSION**

This study has resulted in the Dutch version of the CPIB short form and confirms that the instrument is reliable and valid as well. This is highly relevant, because, for Dutch, no such communicative participation tool was yet available. We chose to translate the 10 item CPIB short form instead of the full 46 item questionnaire. IRT analyses would be the optimal validation method, this was not feasible due to limited resources and sample size requirements. The 10-item version is based on a large enough item set to represent the majority of communication situations, and because of the lower response burden. Moreover, the CPIB short form is well established since it has been used in numerous studies (Baylor et al., 2021). During the pilot testing several minor issues arose, though to maintain uniformity with the original questionnaire no adaptations were made. Regarding cultural adaption, we believe the content of the items did not include culturally different activities between the Dutch and Flemish culture. Moreover, changing the items could have led to measuring a different construct (Harkness, 2003; Harkness et al., 2010).

In this sample of 122 Dutch and Belgian participants, we found excellent internal consistency, a good test–retest reliability and good support for construct validity. We found differences between the subgroups regarding the test–retest reliability, with a lower ICC for the neurological group but acceptable ($> 0.70$).

As presented in Table 2 and Figure 1, acceptable floor and ceiling effects were found for the T1 assessment of the Dutch CPIB short form in both patient populations. Nevertheless, at T1, 12.5% of the head and neck cancer group
obtained the maximum score and at T2, this ceiling effect was seen in 22.9% of the head and neck cancer group. The study design aimed to avoid including participants with rapid change in their speaking capacity via the exclusion criterion ‘being in the acute rehabilitation phase’. Therefore, a change in speaking capacity within these two weeks was not expected. What could have been of influence is the different setting in which T1 and T2 took place. At T1, PROMs were filled out at the institute or hospital right after study assessments, and speech recordings, in the presence of the researcher. In contrast, at T2 the Dutch CPIB short form was completed without other assessments at the participants’ home. Participants might be more comfortable and self-evaluate their communicative participation differently at home than in a hospital setting (Polit, 2014). Another issue probably influencing the ceiling effect found in the head and neck cancer group is the time since diagnosis. As patients were included after rehabilitation it is plausible that the influence on the perceived disability is less, due to acceptance.

Two out of three hypothesis concerning construct validity were confirmed. We hypothesized high correlation \((r = 0.89)\) of the Dutch CPIB short form with the SHI as these PROMs do measure (parts of) the same construct. The high correlation reflects construct validity. Despite the high correlation, we do not consider the measures to be interchangeable, since the focus of the content is different; the CPIB short form focuses on communicative participation in everyday speaking situations which broadens the bandwidth for coverage of this construct compared to the SHI. A moderate instead of a weak correlation with the USER-P frequency subscale was found. The impact of speech difficulties on the frequency of activities is greater than we expected a priori, but still the lowest of all observed correlations, which was consistent with our expectations. The somewhat higher than expected correlation certainly does not imply interchangeability, also because the generic USER-P does not specifically focus on communication in life situations where knowledge, information, ideas, and feelings are exchanged, and therefore has poor content validity for these issues.

Recordings of speech and a listening experiment were included for ratings of the severity of the speech problems. Listening experiments are still considered as the gold standard for grading voice and speech disorders (Darley et al., 1968; Duffy, 2019; Dwivedi et al., 2012). The hypothesized moderate correlation between the Dutch CPIB short form and listening experiment outcomes was confirmed in this study. This listening experiment was performed by senior speech language pathology students. To ensure reliability of the outcomes each fragment was rated by three listeners, high ICC2K outcomes were achieved. A listening experiment is always subjective of nature, with the structured design and the choice for senior speech language pathology students convenient reliability was assured. PROMs are a valuable tool in exploring this construct beyond listening experiments, since PROMs provide more information about how patients deal with their disease and adapt to their limitations. For research purposes and clinical practice, multidimensional assessment of outcomes with a combination of PROMs and perceptual examination, helps to relate best to the concept of patient-centred care and to understand a patient’s perspective and individual treatment goals (Rikkert et al., 2018).

**Strengths and limitations of the study**

A strength of the study is the multi-centre study design, in which we translated and validated the CPIB short form for Dutch. We achieved cross-cultural usability for both Dutch and Flemish Dutch. However, a limitation of the study is that other speaker groups of Dutch (e.g., speakers from Surinam, Netherlands Antilles) were not actively recruited and the history of mother tongue was not systematically documented. Translation and validation procedures were based on rigorous international standards (EORTC and COSMIN). Another strength is the diversity in pathologies of the study participants, as well as including a group of healthy controls.

Although inclusion had to be stopped in February 2020 due to COVID-19, we managed to include 48 HNC patients and 51 neurologic patients, respectively. Attrition was low; 94/100 patients completed T2 assessments. A limitation might be the perceived low level of disability after rehabilitation of the participants, possibly restricting the generalizability to patients who are not yet recovered.

**Clinical implications and future perspectives**

This study provides evidence that the Dutch CPIB short form is a suitable tool in clinical practice and for research purposes to assess communication participation. The CPIB short form focuses entirely on communicative participation, resulting in a wider bandwidth of items compared to current available PROMs as the SHI, VHI, and USER-P. In the field of clinical research this is of great importance since functional and participation outcomes are highly relevant to assess and compare the consequences of acquired speech problems in adults, irrespective of the aetiology.

Future research should aim to further develop the possibilities of using the Dutch CPIB short form in Dutch-speaking patient groups with speech problems due to
other reasons than those included in the present study, as is already been performed for the English version, for example, in voice disorders and aphasia (Baylor et al., 2021). The availability of the CPIB short form in several languages allows researchers and clinicians to compare populations with communicative disorders. For optimal use of the CPIB, we suggest translation and validation of the original 46 items and IRT analysis to produce t-scores for the full item bank. This will also allow assessment of differential item functioning (DIF) to evaluate the extent to which items might be measuring different abilities for members of separate subgroups. Upcoming phenomena in our digitalizing society, such as automatic speech recognition and video conferencing, may warrant further research into the need for additional items related to those areas, to ensure content validity of the CPIB. Pending such new developments, the Dutch CPIB short form is now ready and available for clinical practice and research.

ACKNOWLEDGMENTS
We thank Prof. Frans Hilgers, MD, PhD for establishing the contact between the study team and prof. Tanya Eadie, PhD CCC-SLP, University of Washington and to stimulate this research project. We thank the experts who were involved in the translation procedures, namely Prof. Patrick Cras, MD, PhD, Prof. Neil Aaronson, PhD, Dr. Imogen Cohen, PhD and Elin Derks. The authors acknowledge all personnel at the collaborating study sites who made this study possible. We would like to thank Dr. Katja Batens, PhD, Ingrid Theunkens, and Caroline VandenBruaene who facilitated participant inclusion on their sites. The students who were involved in the data collection, Sandra van de Voorde, Stefanie de Rudder, Lieke Hulshof, Vonne Strijk, Imke Dunnewind and their supervisors are thanked for their efforts. Our gratitude goes to all participants who were involved in the study. [Correction added on XX September, after first online publication: This Acknowledgement section has been added in this version]

CONFLICTS OF INTEREST
The authors have no other funding, financial relationships or conflicts of interest to disclose.

DATA AVAILABILITY STATEMENT
Data available on request due to privacy/ethical restrictions.

FUNDING
The Netherlands Cancer Institute received a research grant from Atos Medical (Malmö, Sweden), which contributed to the existing infrastructure for quality-of-life research of the Department of Head and Neck Oncology and Surgery. The PhD project of E. Passchier was sponsored from the Verweulius Fund.

REFERENCES
Castor, E. (2019) Castor electronic data capture. Amsterdam, the Netherlands: Ciwit BV. Available at: https://castoredc.com
handicap index (VHI) development and validation. American Journal of Speech-Language Pathology, 6, 66–70.


APPENDIX A: DUTCH COMMUNICATIVE PARTICIPATION ITEM BANK—SHORT FORM

Communicatie en participatie item bank 10 item versie, Nederlands

Instructions
De volgende vragen beschrijven een aantal uiteenlopende situaties waarin het nodig kan zijn om te spreken met anderen. Geef voor iedere vraag aan in hoeverre uw aandoening u belemmert om aan de situatie deel te nemen. Met ‘aandoening’ bedoelen we ALLE problemen die de wijze waarop u in die situaties communiceert kunnen beïnvloeden, met inbegrip van spraakproblemen, en andere gezondheidsproblemen of omgevingsfactoren. Als uw spraakkwaliteit varieert, denk dan aan een doorsneeu dag voor uw spraak, niet uw beste of slechtste dag.

<table>
<thead>
<tr>
<th>Item</th>
<th>Helemaal niet (3)</th>
<th>Een beetje (2)</th>
<th>Nogal (1)</th>
<th>Heel erg (0)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Belemmert uw aandoening u in…</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>… het praten met mensen die u kent?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Belemmert uw aandoening u in…</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>… de communicatie als u iets snel wilt zeggen?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Belemmert uw aandoening u in…</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>… het praten met mensen die u NIET kent?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Belemmert uw aandoening u in…</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>… de communicatie in uw leefomgeving (bijv. boodschappen doen, tijdens dokters afspraken, etc.)?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Belemmert uw aandoening u in…</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>… het stellen van vragen tijdens een gesprek?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Belemmert uw aandoening u in…</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>… het communiceren in een kleine groep mensen?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Belemmert uw aandoening u in…</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>… het voeren van een lang gesprek met iemand die u kent, over een boek, film, tv-programma of sportwedstrijd?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Belemmert uw aandoening u in…</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>… het geven van GEDETAILLEERDE informatie?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Belemmert uw aandoening u in…</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>… het aan de beurt komen in een snel verlopend gesprek?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Belemmert uw aandoening u in…</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>… het proberen te overtuigen van een vriend of familie lid om iets van een andere kant te bekijken?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Scoring van de Nederlandse CPIB short form
Voor het berekenen van de totaalscore wordt een somscore berekend. De scores van alle items worden bij elkaarVoor het berekenen van de totaalscore wordt een somscore berekend. De scores van alle items worden bij elkaar opgeteld (Helemaal niet = 3, Een beetje = 2, Nogal, = 1, Heel erg = 0). Een hogere score betekent een betere uitkomst, namelijk minder beperkingen in de communicatieve participatie.
# APPENDIX B: RESULTS OF PILOT TESTING

## Comments of participants during the pilot testing phase

<table>
<thead>
<tr>
<th>Items unclear</th>
<th>Items disturbing</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>NL pt 1</td>
<td>No</td>
<td>Questions were confrontational</td>
</tr>
</tbody>
</table>
| NL pt 2       | Yes             | • question 8: providing detailed information. Why would this take longer or be more difficult?  
• Question 7: what do the examples add? “Long” is clear enough.  
• What exactly do you mean by hindering; psychologically unwilling or physically unable?  
• Difference between long and short speech, in short conversations no obstacle, in long it is.  
• There is one question specifically about long conversations, are the rest of the questions automatically about short conversations?  
• Misses talking in large groups |
| NL pt 3       | Yes             | • Question 9. “I will let others talk”, pt would like to answer not applicable  
• It would be easier if the questions could be answered with yes/no |
| NL pt 4       | No              | • Question 6: it is more difficult for me to communicate with large groups due to hearing loss, not due to my speech problems |
| NL pt 5       | No              | |
| NL pt 6       | No              | • I experience difficulty calling, this could be added |
| NL pt 7       | No              | • question 3 is too general, please specify more.  
• I often experience problems in starting to speak, after a while I can talk more easily |
| NL pt 8       | Yes             | • Question 1: Varies per situation. It goes well in one-on-one conversation, not in groups  
• Question 5: Unclear whether this is one on one or in a group situation  
• Title: unclear title. “item bank” is not Dutch  
• Third sentence in instruction is too long  
• Pt thinks questions 5 and 9 are related, can be asked consecutively  
• Answer options “quite” and “very much” are close to each other in terms of feeling |
| NL pt 9       | No              | • Question 7: I only do this with people I know  
• Question 9: This is not applicable to me, I don’t try this. |
| NL pt 10      | No              | • Question 3: Quite an open door. This is always difficult with strangers, who listen poorly. It would be helpful to include an additional question: do you avoid communication?  
• Question 8: good question |
| BE pt 1       | No              | |
| BE pt 2       | No              | |
| BE pt 3       | No              | letters are staggered in the document. |
| BE pt 4       | No              | |
| BE pt 5       | No              | The asked questions are relevant |
| BE pt 6       | No              | |
| BE pt 7       | Yes             | • Question 4 is unclear |
| BE pt 8       | No              | |
| BE pt 9       | No              | |
| BE pt 10      | No              | |
| BE pt 11      | No              | |
| BE pt 12      | No              | |