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Understanding Patient-Reported Outcome Measures Used in Adult Survivors Experiencing Long-Term Effects After COVID-19 Infection: A Rapid Review

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Purpose
Patient-reported outcome measures (PROMs) are used in individuals experiencing long-term effects from COVID-19 infection, or Long COVID, to evaluate the quality of life and functional status of these individuals. However, little is known about which PROMs are being utilised and the psychometric properties of these PROMs. Our purpose was thus to explore which PROMs are used in Long COVID patients and to discuss the psychometric properties of the PROMs.

Methods
For this rapid review, a systematic literature search was performed in the PubMed, Embase, and CINAHL databases. The found studies were screened using the PRISMA flowchart. We then performed study quality appraisal and assessed the psychometric properties of the found PROMs.

Results
Per the systematic literature search and after removal of duplicates, 157 publications were identified for individual screening. After screening and eligibility assessment, 74 articles were selected for our review. In total, 74 PROMs were used and primarily comprised quality of life, fatigue, breathlessness, mental health, and smell/taste issues in COVID “long haulers.” Five studies used newly developed, COVID-19-specific PROMs. We assessed the psychometric properties of the 10 most-used PROMs. The majority were found to be reliable and valid instruments. EQ-5D-5L was the most popular and highly rated PROM.

Conclusions
We assessed PROMs used in Long COVID patients and evaluated their psychometric properties. EQ-5D-5L was the most favourably rated PROM. PROMs addressing mental health issues are crucial in managing anxiety and depression in Long COVID patients. New COVID-specific PROMs assess functional status and smell/taste perception and show great utilisation potential in olfactory training at COVID smell clinics. However, many reviewed PROMs currently lack sufficient analysis of their psychometric properties. Therefore, future research needs to examine these measures. (J Patient Cent Res Rev. 2024;11:36-50.)

Keywords
quality of life; COVID-19; patient-centered care
When moving forward, it is vital to choose the PROMs based on their measurement properties, such as reliability, validity, or responsivity.

The aim of this rapid review was to explore and describe which PROMs are used in adults suffering from Long COVID and to discuss the psychometric properties of these PROMs.

**METHODS**

**Search Strategy**
For this rapid review, a systematic literature search identified all relevant articles regarding PROMs for adults dealing with long-term consequences after COVID-19 infection. The search included the PubMed, Embase, and CINAHL databases and focused on literature published between April 2020 and June 2022. During our PubMed database search, we used the provided COVID-19 filters from PubMed Clinical Queries (we selected “COVID-19” under “Filter category” and “Long COVID” under “Filter”). The full list of keywords used for the literature search can be found in Online Appendix A.

**Selection of Literature**
The studies in the search were screened using the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) flowchart. Inclusion criteria were published articles in which the study population comprised adults of any gender who survived the COVID-19 infection and were experiencing long-term effects. These articles outlined the use of PROMs for the selected study population. Conference abstracts, poster presentations, study protocols, case studies, systematic reviews, and literature published in any other language than English were excluded. The record screening stage involved 3 independent assessors (E.B., H.W., and M.B.H.) selecting potential studies based on their titles or abstracts. The final decision regarding article eligibility for this review was made after full-text articles were retrieved and assessed.

**Study Quality Assessment**
Key study and patient demographic information, along with specific features of PROMs discussed in our selected studies, was extracted from full-text articles. The quality of the chosen papers was independently assessed by 3 assessors (E.B., H.W., and M.B.H.) through the quality appraisal process, as outlined by Hawker et al. The protocol’s rating for assessing these different study criteria included “good,” “fair,” “poor,” and “very poor” evaluations. These evaluations were then assigned different points: “good” = 4 points, “fair” = 3 points, “poor” = 2 points, and “very poor” = 1 point. The study quality was then ranked by the total study points: high quality (A) = 30–36 points, medium quality (B) = 24–29 points, and low quality (C) = 9–23 points.

**PROM Psychometric Property Evaluation**
The reported psychometric properties (reliability, validity, responsivity, interpretability, and feasibility) of PROMs from the reviewed articles were summarised according to the operational definitions indicated by Stinson et al. Reliability refers to the degree of stability and reproducibility of a PROM when no clinical changes are observed. Validity is concerned with whether a tool measures what it is intended to measure. Responsivity refers to the PROM’s sensitivity to differences in clinical changes over time. Interpretability is concerned with how meaningful the PROM’s results are, while feasibility defines how easily the tool can be scored and interpreted. A plus (“+”) sign indicates confirmation that the PROM contains the psychometric feature, a minus (“−”) sign indicates that the PROM lacks the psychometric feature, and a question mark (“?”) indicates that there is currently no information about whether the PROM contains the psychometric feature.

**RESULTS**
Our search of the 3 literature databases resulted in 157 identified articles (after removal of duplicates). When screening the titles and abstracts, we determined that 107 papers met the inclusion criteria. Our eligibility assessment resulted in 74 articles being selected for our review (Figure 1).

**Characteristics of Selected Studies**
Relevant study characteristics are summarised in Table 1. A full table containing study data extraction can be found in Online Supplemental Table S1. Out of the 74 studies, the majority (n=39) were cohort studies. The study sample size had a wide range, varying from 27 to 5,946 patients. Median patient ages ranged from 18 to 86 years, with median age for nearly two-thirds of the studies (n=45) being ≥50 years old.

The studies were mainly based in a community setting and in outpatient clinics during a COVID-19 follow-up appointment. Nonhospitalised or mild COVID-19 patients made up the majority of the study participants in half of the articles (n=37). Most hospitalised patients did not require invasive mechanical ventilation or ICU admission/critical care.

In total, 74 PROMs were used in our reviewed studies. The vast majority were generic measures, while 24 focused on specific psychiatric, cardiovascular, or respiratory illnesses. Five measures were newly developed for
COVID-19. They captured the impact of COVID-19 on patients’ mental health, smell or taste, and recovery process after acute disease. The time points when study participants were assessed with PROMs ranged from 4 weeks to 15 months. Thirty-seven studies (50%) administered their PROMs 6 months after acute illness, while only 11 publications used their PROMs one year after initial disease. The methods of PROM administration were online questionnaire, telephone/video interview, or face-to-face appointment. PROMs were most often administered during in-person consultations, while online surveys were used least. The majority of the studies, which only enabled online participation, investigated a younger cohort (median patient age <50 years).

Quality Appraisal of Included Studies
A detailed study quality assessment based on the Hawker et al. tool is outlined in Supplemental Table S2.7-79 Nearly 70% of the research was considered high quality (grade A), 19 studies were of medium quality (grade B), and 3 studies were considered low quality (grade C).

In terms of the study abstract, the majority of the papers (n=35) received a fair score, as they lacked some key information in the methods and results sections. The introduction was mainly viewed as good (n=34) or fair (n=32). Publication introductions received fair or poor scores due to the lack of sufficient background or a clearly stated aim of the study.
### Table 1. Characteristics of Included Studies

<table>
<thead>
<tr>
<th>Study design and article reference</th>
<th>Sample size</th>
<th>PROMs used</th>
<th>PROM area of focus</th>
<th>When PROM was used</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Observational study:</strong></td>
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<tr>
<td>Chaumont et al. (2022)³</td>
<td>60</td>
<td>a) EQ-5D-3L b) MoCABlind scale c) CDS d) HADS e) TSS</td>
<td>a) Health-related quality of life b, c) Cognition d) Anxiety/depression e) Smell/taste dysfunction</td>
<td>6 months after acute illness</td>
</tr>
<tr>
<td>Frésard et al. (2022)⁶</td>
<td>51</td>
<td>a) HADS b) CRQ</td>
<td>a) Anxiety/depression b) Health-related quality of life in patients with chronic respiratory disease</td>
<td>119 (±89) days after acute illness</td>
</tr>
<tr>
<td>Rass et al. (2022)⁹</td>
<td>906</td>
<td>a) PHQ-4 b) PHQ stress module</td>
<td>a) Anxiety/depression b) Stress</td>
<td>Austria cohort - 180 (IQR, 130–220) days since diagnosis Italy cohort - 140 (IQR, 120–270) days since diagnosis</td>
</tr>
<tr>
<td>Rossato et al. (2021)¹⁰</td>
<td>201</td>
<td>a) EQ-5D b) FACIT-Fatigue questionnaire c) Chalder Fatigue Scale</td>
<td>a) Health-related quality of life b) Chronic fatigue c) Mental fatigue</td>
<td>65 (IQR, 58–74) days after disease onset</td>
</tr>
<tr>
<td>Scherlinger et al. (2021)¹¹</td>
<td>30</td>
<td>a) SF-36 b) HAQ c) HADS d) PCL-5</td>
<td>a, b) Health-related quality of life c) Anxiety/depression d) Post-traumatic stress disorder</td>
<td>224 (IQR, 202–238) days after symptom onset</td>
</tr>
<tr>
<td>Sperling et al. (2022)¹²</td>
<td>218</td>
<td>a) FAS b) HADS</td>
<td>a) Fatigue b) Anxiety/depression</td>
<td>127.7 (IQR,122.2–133.1) days after discharge</td>
</tr>
<tr>
<td>Zangrillo et al. (2022)¹³</td>
<td>56</td>
<td>a) GOSe b) Functional Ambulation Classification c) Borg dyspnoea scale d) EQ-5D-5L e) HADS g) Insomnia Severity Index</td>
<td>a) Physical recovery and disability b) Autonomy in walking c) Breathlessness d) Health-related quality of life e) Anxiety/depression g) Insomnia</td>
<td>349 (IQR, 343–356) days after discharge</td>
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<tr>
<td><strong>Case-control study:</strong></td>
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<tr>
<td>Carter et al. (2022)¹⁴</td>
<td>32</td>
<td>a) POMS b) PFSDQ-M c) GSLTPAQ</td>
<td>a) Mood b) Functional status c) Physical exercise</td>
<td>85 (±61) days after diagnosis</td>
</tr>
<tr>
<td>Elkan et al. (2021)¹⁵</td>
<td>66</td>
<td>a) RAND-36</td>
<td>a) Health-related quality of life</td>
<td>9 (IQR, 6–9) months after acute illness</td>
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<tr>
<td><strong>Cohort study:</strong></td>
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<tr>
<td>Aparisi et al. (2021)¹⁶</td>
<td>70</td>
<td>a) KCCQ</td>
<td>a) Health-related quality of life in patients with heart failure</td>
<td>Mean follow-up time of second visit 181 (± 42) days</td>
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<tr>
<td>Betschart et al. (2021)¹⁷</td>
<td>43</td>
<td>a) EQ-5D-5L b) PCFS scale c) HADS d) mMRC dyspnoea scale</td>
<td>a) Health-related quality of life b) Recovery status after COVID-19 c) Anxiety/depression d) Breathlessness</td>
<td>3 and 12 months after discharge</td>
</tr>
<tr>
<td>Bouteleux et al. (2021)¹⁸</td>
<td>39</td>
<td>a) mMRC dyspnoea scale b) Borg dyspnoea scale c) VQ-11 questionnaire d) HADS</td>
<td>a, b) Breathlessness c) Health-related quality of life d) Anxiety/depression</td>
<td>73 (IQR, 34–178) days after symptom onset</td>
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<tr>
<td>Catalán et al. (2021)¹⁹</td>
<td>76</td>
<td>a) SF-36</td>
<td>a) Quality of life</td>
<td>1 year after COVID-19 infection</td>
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<tr>
<td>Chand et al. (2022)²⁰</td>
<td>126</td>
<td>a) PHQ-9 &amp; PHQ-2 b) PC-PTSD-5 c) PCFS scale</td>
<td>a) Depression b) Post-traumatic stress disorder c) Recovery status after COVID-19</td>
<td>120 days after discharge</td>
</tr>
<tr>
<td>Comelli et al. (2022)²¹</td>
<td>456</td>
<td>a) mMRC dyspnoea scale</td>
<td>a) Breathlessness</td>
<td>12 months after discharge</td>
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Continued
### Table 1 (cont). Characteristics of Included Studies

<table>
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<th>Study design and article reference</th>
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<th>PROMs used</th>
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<tr>
<td>Daher et al. (2020)</td>
<td>33</td>
<td>a) PHQ-9</td>
<td>a, b) Anxiety/depression</td>
<td>56 (IQR,48–71) days after discharge</td>
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<td></td>
<td></td>
<td>b) GAD-7</td>
<td>c, d) Health-related quality of life</td>
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<td></td>
<td></td>
<td>c) SGRQ</td>
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<td></td>
<td></td>
<td>d) EQ-5D-5L</td>
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<td>Gérard et al. (2022)</td>
<td>288</td>
<td>a) American Thoracic Society Scale</td>
<td>a) Breathlessness</td>
<td>6 months after discharge</td>
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<td>b) WHO/Zubrod Performance Status Scale</td>
<td>b) Health status</td>
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<td>c) IPAQ-SF</td>
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<td>González et al. (2021)</td>
<td>62</td>
<td>a) mMRC dyspnoea scale</td>
<td>a) Breathlessness</td>
<td>3 months after discharge</td>
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<td></td>
<td>b) SF-12</td>
<td>b) Health-related quality of life</td>
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<td>c) HADS</td>
<td>c) Anxiety/depression</td>
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<td>Graham et al. (2021)</td>
<td>76</td>
<td>a) PROMIS assessment</td>
<td>a) Quality of life in cognition and fatigue</td>
<td>5.27 months after symptom onset</td>
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<td>Gossain et al. (2021)</td>
<td>2198</td>
<td>a) PCFS scale</td>
<td>a) Recovery status after COVID-19</td>
<td>4 and 12 weeks after acute illness</td>
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<tr>
<td>Huang et al. (2021)</td>
<td>1276</td>
<td>a) EQ-5D-5L</td>
<td>a) Health-related quality of life</td>
<td>6 and 12 months after discharge</td>
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<tr>
<td></td>
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<td>b) mMRC dyspnoea scale</td>
<td>b) Breathlessness</td>
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<tr>
<td>Kim et al. (2022)</td>
<td>170</td>
<td>a) EQ-5D-5L</td>
<td>a) Health-related quality of life</td>
<td>193 (IQR, 188–206) days and 381.6 ±8.8 days after acute illness</td>
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<td>b) mMRC dyspnoea scale</td>
<td>b) Breathlessness</td>
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<td></td>
<td></td>
<td>c) PHQ-9</td>
<td>c) Mental health status</td>
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<td></td>
<td>d) GAD-7</td>
<td>d) Post-traumatic stress disorder</td>
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<td>e) PCL-5</td>
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<td>Kingery et al. (2021)</td>
<td>530</td>
<td>a) SF-36</td>
<td>a) Health-related quality of life</td>
<td>332 (IQR, 325–344) days after discharge</td>
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<td>Liu et al. (2022)</td>
<td>1438</td>
<td>a) IQCODE</td>
<td>a) Dementia</td>
<td>6 and 12 months after acute illness</td>
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<td>Lorent et al. (2022)</td>
<td>299</td>
<td>a) SF-36</td>
<td>a) Health-related quality of life</td>
<td>82 (IQR, 60–115) days and 387 (IQR, 363–419) days hospitalisation</td>
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<td></td>
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<td>b) HADS</td>
<td>b) Anxiety/depression</td>
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<td>Malinowska et al. (2021)</td>
<td>67</td>
<td>a) mMRC dyspnoea scale</td>
<td>a) Breathlessness</td>
<td>6 months after diagnosis</td>
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<td>b) EQ-5D-5L</td>
<td>b) Health-related quality of life</td>
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<td>Magdy et al. (2022)</td>
<td>85</td>
<td>a) SF 36</td>
<td>a) Health-related quality of life</td>
<td>3 and 6 months after disease onset</td>
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<tr>
<td>Makaronidis et al. (2021)</td>
<td>467</td>
<td>a) Symptom questionnaire</td>
<td>a) Smell and/or taste loss</td>
<td>4-6 weeks after SARS-CoV-2 IgG/IgM antibody testing</td>
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<tr>
<td>Malinowska et al. (2021)</td>
<td>67</td>
<td>a) mMRC dyspnoea scale</td>
<td>a) Breathlessness</td>
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<tr>
<td></td>
<td></td>
<td>b) EQ-5D-5L</td>
<td>b) Health-related quality of life</td>
<td></td>
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<tr>
<td>McFann et al. (2021)</td>
<td>62</td>
<td>a) RAND-36</td>
<td>a) Health-related quality of life</td>
<td>125.3 (±71.8) days since diagnosis</td>
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<tr>
<td>Miskowiak et al. (2021)</td>
<td>29</td>
<td>a) EQ-5D-5L</td>
<td>a) Quality of life</td>
<td>4 months after hospitalisation for COVID-19</td>
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<td></td>
<td></td>
<td>b) MRC dyspnoea scale</td>
<td>b) Breathlessness</td>
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<td></td>
<td></td>
<td>c) WPAI</td>
<td>c) Work productivity and activity impairment</td>
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<td>Morin et al. (2021)</td>
<td>478</td>
<td>a) SF-36</td>
<td>a) Health-related quality of life</td>
<td>125 (IQR, 107–144) days after discharge</td>
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<td></td>
<td></td>
<td>b) Multidimensional Fatigue Inventory scale</td>
<td>b) Fatigue</td>
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<td></td>
<td>c) HADS</td>
<td>c) Anxiety/depression</td>
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<td>d) Beck Depression Inventory score</td>
<td>d) Depression</td>
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<td></td>
<td></td>
<td>e) Insomnia Severity Index</td>
<td>e) Insomnia</td>
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<td></td>
<td></td>
<td>f) PCL-5</td>
<td>f) Post-traumatic stress disorder</td>
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<td>Munblit et al. (2021)</td>
<td>2,649</td>
<td>a) MRC dyspnoea scale</td>
<td>a) Breathlessness</td>
<td>Median follow-up time post-discharge - 217.5 (IQR, 200.4–235.5) days</td>
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<td>b) EQ-5D-5L</td>
<td>b) Health-related quality of life</td>
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<td></td>
<td></td>
<td>c) WG Short Form</td>
<td>c, d) Disability</td>
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<td>d) WHODAS 2.0</td>
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<table>
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<tr>
<th>Study design and article reference</th>
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<th>PROMs used</th>
<th>PROM area of focus</th>
<th>When PROM was used</th>
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</thead>
<tbody>
<tr>
<td>Nopp et al. (2022)&lt;sup&gt;39&lt;/sup&gt;</td>
<td>58</td>
<td>a) PCFS scale b) MRC dyspnoea scale c) Borg dyspnoea scale d) FAS e) EQ-5D-5L</td>
<td>a) Recovery status after COVID-19 b) Breathlessness c) Fatigue d) Health-related quality of life</td>
<td>At the end of 6-week rehabilitation which started 4.4 (±2) months after positive COVID-19 test</td>
</tr>
<tr>
<td>Och et al. (2021)&lt;sup&gt;40&lt;/sup&gt;</td>
<td>79</td>
<td>a) mMRC dyspnoea scale b) EQ-5D-5L</td>
<td>a) Breathlessness b) Health-related quality of life</td>
<td>3 and 6 months after discharge</td>
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<tr>
<td>Prampart et al. (2022)&lt;sup&gt;41&lt;/sup&gt;</td>
<td>198</td>
<td>a) mMRC dyspnoea scale b) K10 scale</td>
<td>a) Breathlessness b) Psychological distress</td>
<td>9 (±2) months</td>
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<tr>
<td>Rogers-Brown et al. (2021)&lt;sup&gt;42&lt;/sup&gt;</td>
<td>1295</td>
<td>a) PROMIS b) Neuro-QoL</td>
<td>a) Health-related quality of life in neurological disorders</td>
<td>Not specified</td>
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<tr>
<td>Seeßle et al. (2021)&lt;sup&gt;44&lt;/sup&gt;</td>
<td>96</td>
<td>a) SF-12</td>
<td>a) Health-related quality of life</td>
<td>5 months, 9 months and 12 months after symptom onset</td>
</tr>
<tr>
<td>Sigfrid et al. (2021)&lt;sup&gt;45&lt;/sup&gt;</td>
<td>327</td>
<td>a) EQ-5D-5L b) MRC dyspnoea scale c) WG Short Form</td>
<td>a) Quality of life b) Breathlessness c) Disability</td>
<td>222 (IQR, 189–269) days after symptom onset</td>
</tr>
<tr>
<td>Sonnweber et al. (2022)&lt;sup&gt;46&lt;/sup&gt;</td>
<td>108</td>
<td>a) BRCS b) CFS questionnaire c) EQ-5D-5L</td>
<td>a) Resilient coping b) Fatigue c) Health-related quality of life</td>
<td>60, 100, 180 and 360 days after acute illness</td>
</tr>
<tr>
<td>Sun et al. (2022)&lt;sup&gt;47&lt;/sup&gt;</td>
<td>534</td>
<td>a) mMRC dyspnoea scale b) GAD-7 c) PHQ-9 d) ASI e) EQ-5D-5L f) PCFS scale</td>
<td>a) Breathlessness b) Anxiety c) Depression d) Insomnia e) Health-related quality of life f) Recovery status after COVID-19</td>
<td>460 (IQR, 451–467) days after disease onset</td>
</tr>
<tr>
<td>Vaes et al. (2021)&lt;sup&gt;48&lt;/sup&gt;</td>
<td>239</td>
<td>a) WPAI b) PCFS scale c) EQ-5D-5L</td>
<td>a) Work productivity and activity impairment b) Recovery status after COVID-19 c) Health-related quality of life</td>
<td>10.4 (±2.4) weeks and 22.6 (±2.4) weeks after symptom onset</td>
</tr>
<tr>
<td>Van Herck et al. (2021)&lt;sup&gt;49&lt;/sup&gt;</td>
<td>239</td>
<td>a) CIS-Fatigue</td>
<td>a) Fatigue</td>
<td>10.4 (±2.4) and 22.6 (±2.4) weeks after acute disease</td>
</tr>
<tr>
<td>Vandersteen et al. (2022)&lt;sup&gt;50&lt;/sup&gt;</td>
<td>43</td>
<td>a) QOD-NS b) SF-36</td>
<td>a) Olfactory quality of life b) Health-related quality of life</td>
<td>5.8 (±3.2) months and 11 (±3.7) months</td>
</tr>
<tr>
<td>Walle-Hansen et al. (2021)&lt;sup&gt;51&lt;/sup&gt;</td>
<td>106</td>
<td>a) EQ-5D-5L</td>
<td>a) Health-related quality of life</td>
<td>6 months after hospitalisation</td>
</tr>
<tr>
<td>Weerahandi et al. (2021)&lt;sup&gt;52&lt;/sup&gt;</td>
<td>161</td>
<td>a) PROMIS pulmonary instrument b) PROMIS overall health status instrument</td>
<td>a) Breathlessness b) Health-related quality of life</td>
<td>30–40 days after discharge</td>
</tr>
<tr>
<td>Zhan et al. (2021)&lt;sup&gt;53&lt;/sup&gt;</td>
<td>121</td>
<td>a) mMRC dyspnoea scale</td>
<td>a) Breathlessness</td>
<td>316 (IQR, 311–321) days after discharge</td>
</tr>
</tbody>
</table>

**Cross-sectional study:**

<table>
<thead>
<tr>
<th>Study design and article reference</th>
<th>Sample size</th>
<th>PROMs used</th>
<th>PROM area of focus</th>
<th>When PROM was used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Albu et al. (2021)&lt;sup&gt;54&lt;/sup&gt;</td>
<td>30</td>
<td>a) MFIS b) PSQI c) WHOQOL-BREF d) HADS e) Functional Independence Measure</td>
<td>a) Impact of fatigue on daily living b) Sleep quality c) Health-related quality of life d) Anxiety/depression e) Independence for self-care</td>
<td>103 (IQR, 93–116) days after symptom onset</td>
</tr>
<tr>
<td>Bonsaksen et al. (2022)&lt;sup&gt;55&lt;/sup&gt;</td>
<td>303</td>
<td>a) GHQ-12 b) Chalder Fatigue Scale c) PSS</td>
<td>a) Psychological distress b) Fatigue c) Stress</td>
<td>Not specified</td>
</tr>
</tbody>
</table>

*Continued*
<table>
<thead>
<tr>
<th>Study design and article reference</th>
<th>Sample size</th>
<th>PROMs used</th>
<th>PROM area of focus</th>
<th>When PROM was used</th>
</tr>
</thead>
</table>
| Bungenberg et al. (2022)\(^\text{56}\) | 50          | a) HADS  
b) EQ-5D-5L  
c) FSMC  
d) PSQI  
e) ESS  
f) EBI | a) Anxiety/depression  
b) Health-related quality of life  
c) Fatigue  
d) Sleep quality  
e) Daytime sleepiness  
f) Level of autonomy in basic everyday functions | 29.3 weeks (IQR, 3.29–57.86) after acute illness |
| Faghy et al. (2022)\(^\text{57}\) | 381         | a) SF-36  
b) PSQI | a) Health-related quality of life  
b) Sleep quality | Not specified |
| Fernandes et al. (2021)\(^\text{58}\) | 45          | a) EQ-5D-5L  
b) WHODAS 2.0 | a) Health-related quality of life  
b) Disability | 55 (IQR, 42–64) days after discharge |
| Förster et al. (2022)\(^\text{59}\) | 1459        | a) EQ-5D-5L | a) Health-related quality of life | 219 (±32.6) days |
| Frontera et al. (2021)\(^\text{60}\) | 76          | a) Neuro-QoL | a) Health-related quality of life in neurological disorders | Prolonged COVID-19 symptoms group - 4 (IQR, 2–9) months since diagnosis  
COVID-19 positive group without prolonged symptoms - 2 (IQR, <1–6) months since diagnosis |
| Giurgi-Oncu et al. (2021)\(^\text{61}\) | 143         | a) PCFS scale  
b) EQ-5D-5L  
c) HADS | a) Recovery status after COVID-19  
b) Health-related quality of life  
c) Anxiety/depression | 4 to 12 weeks after disease onset |
| Henneghan et al. (2021)\(^\text{62}\) | 52          | a) PROMIS  
b) PSS | a) Cognition, psychological wellbeing  
b) Stress | 120 (±95) days since diagnosis |
| Holdsworth et al. (2022)\(^\text{63}\) | 205         | a) Borg dyspnoea scale  
b) FAS  
c) GAD-7  
d) PHQ-9  
e) PCL-5  
f) EQ-5D-5L | a) Breathlessness  
b) Fatigue  
c) Anxiety  
d) Depression  
e) Post-traumatic stress disorder  
f) Health-related quality of life | 24 (IQR, 17.1–34.0) weeks after acute illness |
| Iqbal et al. (2021)\(^\text{64}\) | 158         | a) EQ-5D-5L | a) Quality of life | 38.1 (±20.0) days since recovery |
| Islam et al. (2021)\(^\text{65}\) | 1002        | a) PHQ-9 | a) Depression | Not specified |
| Johnsen et al. (2022)\(^\text{66}\) | 57          | a) CAT  
b) MRC dyspnoea scale  
c) WPQAI  
d) EQ-5D-5L  
e) PCFS scale | a, b) Breathlessness  
c) Work productivity and activity impairment  
d) Health-related quality of life  
e) Recovery status after COVID-19 | 3 months after discharge/resolution of acute disease |
| Kaplan et al. (2022)\(^\text{67}\) | 121         | a) EQ-5D-5L | a) Health-related quality of life | 30.3 (IQR, 12.7–56.9) weeks since diagnosis |
| Lemhöfer et al. (2021)\(^\text{68}\) | 365         | a) RehabNeS  
b) SF-36 | a) Rehabilitation needs for COVID-19 patients  
b) Health-related quality of life | 93.7% participants were 3 months after acute disease |
| Lindahl et al. (2022)\(^\text{69}\) | 101         | a) mMRC dyspnoea scale  
b) RAND-36 | a) Breathlessness  
b) Health-related quality of life | 172 days after discharge |
| Méndez et al. (2021)\(^\text{70}\) | 179         | a) GAD-7  
b) PHQ-2  
c) DTS  
d) SF-12 | a) Anxiety  
b) Depression  
c) Post-traumatic stress disorder  
d) Health-related quality of life | 2 months after discharge |
| Tleyjeh et al. (2022)\(^\text{71}\) | 5946        | a) PCFS scale  
b) MRC dyspnoea scale  
c) CFS questionnaire  
d) WHO-5  
e) MET score | a) Recovery status after COVID-19  
b) Breathlessness  
c) Fatigue  
d) Mental wellbeing  
e) Exercise tolerance | 4 weeks after disease onset |

Continued
Table 1 (cont). Characteristics of Included Studies

<table>
<thead>
<tr>
<th>Study design and article reference</th>
<th>Sample size</th>
<th>PROMs used</th>
<th>PROM area of focus</th>
<th>When PROM was used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Townsend et al. (2021)(^{72})</td>
<td>153</td>
<td>a) Chalder Fatigue Scale</td>
<td>a) Fatigue</td>
<td>75 (IQR, 66–108) days after diagnosis</td>
</tr>
</tbody>
</table>
| Twomey et al. (2022)\(^{73}\)     | 213         | a) FACIT-Fatigue questionnaire  
    b) DSQ-PEM  
    c) SEBQ  
    d) SF-36  
    e) IPAQ-SF | a) Chronic fatigue  
    b) Fatigue, post-exertional malaise, pain, brain fog  
    c) Breathlessness  
    d) Health-related quality of life  
    e) Physical activity | 72.3% of patients have been experiencing symptoms for >6 months |
| van den Borst et al. (2021)\(^{74}\) | 124         | a) HADS  
    b) CFQ  
    c) PCL-5  
    d) IES-R | a) Anxiety/depression  
    b) Self-reported cognitive functioning  
    c) Post-traumatic stress disorder  
    d) Stress reactions after traumatic events | 13.0 (±2.2) weeks after disease onset |
| Ziauddeen et al. (2022)\(^{75}\)   | 675         | a) FSS  
    b) PCFS | a) Fatigue  
    b) Recovery status after COVID-19 | 6.2 (±2.4) months after acute disease |

**Pilot study:**

<table>
<thead>
<tr>
<th>Study design and article reference</th>
<th>Sample size</th>
<th>PROMs used</th>
<th>PROM area of focus</th>
<th>When PROM was used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barin et al. (2021)(^{76})</td>
<td>41</td>
<td>a) Psychological survey</td>
<td>a) Negative psychological experiences regarding COVID-19 diagnosis</td>
<td>Median follow-up time - 2 months post-diagnosis</td>
</tr>
</tbody>
</table>
| Cahalan et al. (2022)\(^{77}\)    | 27          | a) C19-YRS  
    b) DSQ-SF | a) Health-related functioning  
    b) Fatigue, post-exertional malaise, pain, brain fog | 12 (IQR, 4–13) months after acute illness |

**Randomised controlled trial:**

<table>
<thead>
<tr>
<th>Study design and article reference</th>
<th>Sample size</th>
<th>PROMs used</th>
<th>PROM area of focus</th>
<th>When PROM was used</th>
</tr>
</thead>
</table>
| Vlake et al. (2022)\(^{78}\)      | 89          | a) IES-R  
    b) HADS  
    c) SF-36  
    d) EQ-5D-5L  
    e) Patient satisfaction with ICU questionnaire | a) Stress reactions after traumatic events  
    b) Anxiety/depression  
    c) Health-related quality of life  
    d) Patients’ satisfaction with and rating of ICU aftercare | 4 and 6 months after discharge |

**Other:**

<table>
<thead>
<tr>
<th>Study design and article reference</th>
<th>Sample size</th>
<th>PROMs used</th>
<th>PROM area of focus</th>
<th>When PROM was used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lemhöfer et al. (2021)(^{79})</td>
<td>N/A</td>
<td>a) COVID-19 Rehabilitation Needs Survey</td>
<td>a) Functional limitations and rehabilitation needs during and after COVID-19 infection</td>
<td>N/A</td>
</tr>
</tbody>
</table>

ASI, Arabic Scale of Insomnia; BRCS, Brief Resilient Coping Scale; C19-YRS, COVID-19 Yorkshire Rehab Screen; CAT, COPD Assessment Test; CDS, 35-item version of Cognitive Difficulties Scale; CFQ, Cognitive Failure Questionnaire; CIS, Chronic Fatigability Syndrome; CIGS, Checklist Individual Strength; CRQ, Chronic Respiratory Questionnaire; DSQ-PEM, DePaul Symptom Questionnaire–Post-Exertional Malaise; DSQ-SF, DePaul Symptom Questionnaire Short Form; DTS, Davidson Trauma Scale; EBI, Extended Barthel Index; EQ-5D-3L, EuroQol Five-Dimension Three-Level Questionnaire; EQ-5D-5L, EuroQol Five-Dimension Five-Level Questionnaire; ESS, Epworth Sleepiness Scale; FAS, Fatigue Assessment Scale; FSDQ-M, Pulmonary Functional Status and Dyspnoea Questionnaire—Modified; GHQ-12, General Health Questionnaire; GOSe, Glasgow Outcome Scale extended; GSLTPAQ, Godin-Shephard Leisure-Time Physical Activity questionnaire; HADS, Hospital Anxiety and Depression Scale; HAQ, Health Assessment Questionnaire; IES-R, Impact of Event Scale—Revised; IPAQ-SF, International Physical Activity Questionnaire - Short Form; PCFS, Post-COVID-19 Functional Status Scale; PCL-5, Post-traumatic Stress Disorder Checklist-5; PC-PTSD-5, Primary care PTSD Screen for DSM-5; PCSF, Post-COVID-19 Functional Status scale; PCL-5, Post-traumatic Stress Disorder Checklist-5; PC-PTSD-5, Primary care PTSD Screen for DSM-5; PFSDQ-M, Pulmonary Functional Status and Dyspnoea Questionnaire—Modified; PHQ, Patient Health Questionnaire; POMS, Profile of Mood States; PROMIS, Patient-Reported Outcomes Measurement Information System; PSQI, Pittsburgh Sleep Quality Index; PSS, Perceived Stress Scale; QOD-NS, Questionnaire of Olfactory Disorders - Negative Statements; RAND-36, RAND 36-Item Health Survey; RehabNeS, Rehabilitation-Needs-Survey; SEBQ, Self-Evaluation of Breathing Questionnaire; SF-12, 12-item Short Form Survey; SF-36, 36-Item Short Form Survey; SGRQ, St. George’s Respiratory Questionnaire; TSS, Taste and Smell Survey; WG, Washington Disability Group; WHO-5, World Health Organisation-five Well-being Index; WHODAS 2.0, World Health Organisation Disability Assessment Schedule; WHOQOL-BREF, World Health Organisation Quality of Life—BREF; WPAI, Work Productivity and Activity Impairment Questionnaire.

N/A, not applicable.
Approximately two-thirds of the papers presented their methodology and statistical analysis well. Fair/poor scores were given for not providing adequate information about the used PROMs, not discussing statistical significance, or insufficiently detailing the data analysis process. Approximately 60% of studies outlined their sampling and ethical considerations well, with the rest failing to provide information on subject inclusion/exclusion criteria or acknowledge participant consent.

The main issues with study quality involved their transferability and implications. Sixty-six percent of the studies had only fair/poor transferability, since their findings lacked adequate comparison to published research in the same field. Moreover, only 22% of the articles were given good evaluations for their study implications. The rest either did not specify any novel findings or lacked suggestions for future research and implications for current policies.

Assessment of the Psychometric Properties of PROMs

We assessed the psychometric features of 10 PROMs that were most frequently used by our reviewed publications. The evaluations of these PROMs are presented in Table 2. All evaluated PROMs were shown to be reliable (most frequently with test-retest reliability) and valid (most usually with construct validity) measures. Overall, the most validated instruments were the EuroQoL Five-Dimension Five-Level Questionnaire (EQ-5D-5L) and the Patient Health Questionnaire-9 (PHQ-9).

Reliability. Only the PHQ-9 and Hospital Anxiety and Depression Scale (HADS) were confirmed to have interrater reliability, test-retest reliability, and internal consistency. Most PROMs were found to have test-retest reliability (n=9), while half had demonstrated internal consistency.

Validity. Only construct validity was reported in the vast majority of studies (n=9). Four PROMs contained 2 or more properties that measured validity. Only EQ-5D-5L had been confirmed to contain 3 validity properties.

Responsivity. Half of the reviewed PROMs were confirmed to have responsivity. The MRC dyspnoea scale was reported to lack this property, since patients rarely get better or decline to a level required for their MRC grade of breathlessness to change.31

Interpretability. Only 3 PROMs were reported to have interpretability. This psychometric property was limited in the 36-Item Short Form Survey (SF-36) because its total score failed to give clinically relevant information

<table>
<thead>
<tr>
<th>PROM name/ acronym</th>
<th>No. of evaluations</th>
<th>Reliability</th>
<th>Validity</th>
<th>Responsivity</th>
<th>Interpretability</th>
<th>Feasibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>EQ-5D-5L</td>
<td>80-82</td>
<td>+ + + + + + + + + +</td>
<td>+ + + + + + + + + +</td>
<td>+ + + + + + + + + +</td>
<td>+ + + + + + + + + +</td>
<td>+ + + + + + + + + +</td>
</tr>
<tr>
<td>MRC dyspnoea</td>
<td>19</td>
<td>+ + + + + + + + + +</td>
<td>+ + + + + + + + + +</td>
<td>+ + + + + + + + + +</td>
<td>+ + + + + + + + + +</td>
<td>+ + + + + + + + + +</td>
</tr>
<tr>
<td>HADS</td>
<td>15</td>
<td>+ + + + + + + + + +</td>
<td>+ + + + + + + + + +</td>
<td>+ + + + + + + + + +</td>
<td>+ + + + + + + + + +</td>
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</tr>
<tr>
<td>PCFS scale</td>
<td>10</td>
<td>+ + + + + + + + + +</td>
<td>+ + + + + + + + + +</td>
<td>+ + + + + + + + + +</td>
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<tr>
<td>SF-36</td>
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<tr>
<td>PHQ-9</td>
<td>6</td>
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<td>+ + + + + + + + + +</td>
<td>+ + + + + + + + + +</td>
<td>+ + + + + + + + + +</td>
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</tr>
<tr>
<td>GAD-7</td>
<td>5</td>
<td>+ + + + + + + + + +</td>
<td>+ + + + + + + + + +</td>
<td>+ + + + + + + + + +</td>
<td>+ + + + + + + + + +</td>
<td>+ + + + + + + + + +</td>
</tr>
<tr>
<td>PCL-5</td>
<td>5</td>
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<td>+ + + + + + + + + +</td>
<td>+ + + + + + + + + +</td>
<td>+ + + + + + + + + +</td>
<td>+ + + + + + + + + +</td>
</tr>
<tr>
<td>Borg Dyspnoea Scale</td>
<td>4</td>
<td>+ + + + + + + + + +</td>
<td>+ + + + + + + + + +</td>
<td>+ + + + + + + + + +</td>
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<tr>
<td>WPAI</td>
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<td>+ + + + + + + + + +</td>
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<td>+ + + + + + + + + +</td>
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</tbody>
</table>
regarding the patient responses to individual domains of the survey. Six instruments are yet to be evaluated for interpretability.

Feasibility. Feasibility was confirmed in the vast majority (n=9) of PROMs. Only Post-traumatic Stress Disorder (PTSD) Checklist-5 (PCL-5) currently lacks information on this psychometric property.

DISCUSSION

Our rapid review found 74 PROMs that were used in Long COVID patients. The main areas of their focus were general health-related quality of life, breathlessness, fatigue, and mental health issues. PROMs specifically developed for COVID-19 explored patients’ psychological wellbeing, smell/taste perception, and the process of recovery from acute illness.

EQ-5D-5L – the Most Popular and Highly Rated PROM

EQ-5D-5L was the most frequently used measure in our review. This PROM measures overall quality of life, basing it on variables including mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. The patient chooses an answer for every variable from Level 1 (“no problems”) to Level 5 (“extreme problems”). It has been translated into 169 languages and is widely used by research studies and healthcare systems. According to our review, EQ-5D-5L was amongst the most favourably rated PROMs, with confirmed responsivity, interpretability, feasibility, and partially verified reliability and validity. This measure was also used by a third of all studies, the vast majority of which were highly rated publications. Therefore, current evidence suggests that the EQ-5D-5L can be recommended for assessing health-related quality of life in Long COVID patients.

The Importance of Mental Health-Related PROMs in Long COVID

PROMs that address psychological symptoms could be a very useful tool in patients with Long COVID. A recent review identified the rates of individuals suffering from anxiety after acute COVID-19 illness to range from 6.5 to 63%. Depression and PTSD have been reported in 12% to nearly 50% of COVID-19 survivors several months after disease onset. A wide range of reported prevalence of mental health issues could be attributed to differences in outcome measures used by various studies. Out of the 10 most frequently used PROMs, 4 were focused on mental health. HADS was the most commonly utilised mental health PROM in our study. HADS comprises 2 subscales – anxiety (HADS-A) and depression (HADS-D). The HADS-A consists of items including tension, worry, fear, panic, difficulties in relaxing, and restlessness, whereas HADS-D focuses on measuring anhedonia. Patient responses are rated on a 4-point Likert scale, with higher scores corresponding to higher severity. HADS has been rated strongly for its reliability, validity, and responsivity, while its interpretability is yet to be reported. Therefore, it is a useful tool to quickly evaluate patients’ mental wellbeing, which can significantly influence treatment outcomes. However, some studies are sceptical about the reliability of using the 2 subscales of HADS as independent measures.

For separate depression and anxiety assessments, PHQ-9 and Generalized Anxiety Disorder-7 (GAD-7), respectively, were used. PHQ-9 is a 9-item questionnaire that explores sleep, exhaustion, appetite, concentration, and suicidal ideation over the previous 2 weeks. PHQ-9 has been concluded to have good diagnostic validity and responsivity, so it is a suitable measure to identify depression, its severity, and patients’ response to treatment. GAD-7 is a 7-item tool that assesses for generalised anxiety disorder over the previous 2 weeks. The scale score ranges from 0 to 21, with higher scores correlating to stronger anxiety. This PROM has been widely used by general practitioners when screening for anxiety. We found GAD-7 to be a generally reliable and valid measure. However, evidence regarding its responsivity and interpretability is still scarce, making it difficult to evaluate changes in patients’ anxiety. Both PHQ-9 and GAD-7 are helpful mental health-related measures when separately screening for depression and anxiety, while HADS can be used to effectively measure general psychological distress. Future work should focus on developing an effective tool in evaluating both general and individual mental health issues.

Newly Established PROMs Specifically for COVID-19

Our paper identified 5 PROMs newly designed for Long COVID. The most frequently used measure has been the Post-COVID-19 Functional Status (PCFS) scale. PCFS is concerned with the recovery and self-reported functional status of patients after acute COVID-19 disease. It was first established to measure functional sequelae after venous thromboembolism. However, due to the cardiopulmonary nature of COVID-19, the scale was assumed to be relevant to patients with COVID-19. The PCFS scale evaluation comprises 5 grades: grade 0 (no functional limitations), grade 1 (negligible functional limitations), grade 2 (slight functional limitations), grade 3 (moderate functional limitations), grade 4 (severe functional limitations), and grade 5 (death). This PROM has good intrarater reliability, while the other psychometric properties are yet to be explored. PCFS is also easy to use, which is a major advantage when considering its wider implementation. The vast majority of papers that used the PCFS scale
were ranked as high quality. Therefore, this tool could prove useful when examining patients’ functional status after acute COVID-19 infection.

One of the most striking symptoms of COVID-19, affecting 65%–70% of COVID-19 patients, is smell and taste loss. Thus, it has been crucial to develop a measure that could examine olfactory symptoms and how they change with Long COVID. Makaronidis et al. introduced a new questionnaire focused on altered smell/taste. The baseline survey inquired whether patients had any changes in their smell/taste and asked them to provide details of these changes. The follow-up questionnaire was administered 4–6 weeks later and inquired whether previously mentioned symptoms had resolved. The publication was highly rated via the Hawker et al. tool, and the questionnaire seems to be an interpretable and feasible measure. However, it requires more thorough assessment for its reliability, validity, and responsivity. Other smell-related PROMs have also been used in patients with Long COVID. One pilot study used a validated English Olfactory Disorders Questionnaire (eODQ) to determine the impact of smell loss on post-acute COVID-19 patients’ quality of life. They administered the PROM on 20 participants with a history of persistent olfactory dysfunction for the past 3 months. eODQ is much more meticulous than the questionnaire by Makaronidis et al., but it is significantly longer, which could put some patients off. Nevertheless, these PROMs could be essential in helping patients with Long COVID who have experienced smell loss. There are attempts to establish COVID-19 smell clinics, where olfactory training will aid smell recovery after acute COVID-19 infection. Smell-focused PROMs could be utilised to determine the levels of smell and related quality of life in these clinics after the completion of olfactory training.

Study Strengths and Limitations
Our review has multiple strengths. To our knowledge, this is the first study critically reviewing the psychometric properties of commonly used PROMs in patients with Long COVID, while also assessing the methodological quality of studies reporting on these tools. This topic is relevant to the still-developing situation regarding the resolution of the COVID-19 pandemic, and managing long-term COVID consequences will be a key factor in achieving this. We also completed a comprehensive literature search in multiple databases with 3 independent reviewers and followed the newly developed and up-to-date PRISMA guidelines for research reporting, which ensured a transparent, systematic, and accurate method of reporting.

This study also has several limitations. The situation regarding the COVID-19 pandemic is still evolving as we find out new information about the virus, and this influences the sensitivity of our research. In addition, studies that involve the use of PROMs are always subject to recall bias. Furthermore, 42% of our reviewed publications administered their PROMs less than 6 months after the initial COVID-19 infection. Thus, it would be useful for future studies to conduct research longitudinally via several time points that could evaluate trends in more detail. Lastly, several of our reviewed articles had ethnicity and socio-economic biases, so more equal representation is needed in future research on this subject.

CONCLUSIONS
This rapid review presents an assessment of currently used PROMs in patients with Long COVID and an evaluation of the psychometric properties of the PROMs. The examined PROMs addressed the quality of life, fatigue, breathlessness, psychological struggles, and olfactory difficulties in COVID “long haulers.” EQ-5D-5L was the best-rated and most frequently used tool. Most of our reviewed PROMs were reliable and valid instruments, while their responsivity and interpretability still lacked sufficient analysis. Furthermore, 42% of our reviewed studies examined patients with Long COVID who were acutely unwell less than 6 months prior. The use of PROMs by clinicians in patients with Long COVID could improve their understanding of disease symptoms and help track the resolution of illness. Therefore, future research needs to focus on providing data on patients at multiple time points during their recovery and test the key psychometric features of the examined PROMs to obtain reliable evidence that could improve current practices.

Patient-Friendly Recap
• Approximately 30%–50% of individuals with COVID-19 have lingering symptoms that can last up to one year.
• Effectively identifying these “Long COVID” cases is still problematic, and researchers are trying to use patient-reported outcome measures, or PROMs, to capture the quality of life, daily functioning, and symptoms from the perspective of Long COVID sufferers.
• This review explored which PROMS are used in Long COVID sufferers and discussed the psychometric properties of these PROMs.
• The examined PROMs addressed the quality of life, fatigue, breathlessness, psychological struggles, and difficulties related to sense of smell in individuals with Long COVID, and the best-rated, most frequently used PROM was identified and recommended for clinicians.
Author Contributions
Study design: Barilaite, Hocaoglu. Data acquisition or analysis: all authors. Manuscript drafting: Barilaite. Critical revision: all authors.

Conflicts of Interest
None.

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