


# BMJ Open Psychometric properties of the living with long term conditions scale in an English-speaking population living with long term conditions in the UK

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## ABSTRACT

**Objective** To present the psychometric properties of the living with long-term condition (LwLTCs) scale in an English-speaking population of people with different LTCs.

**Design** An observational and cross-sectional study, with retest was conducted. Psychometric properties including feasibility, internal consistency, confirmatory factor analysis, reproducibility and content validity were tested.

**Setting** The study took place across the UK via primary care surgeries and voluntary organisations, between December 2021 and June 2022.

**Participants** The study included 577 patients living with different LTCs, as chronic obstructive pulmonary disease, arthritis, chronic heart failure, Parkinson's disease, chronic kidney disease and type 2 diabetes mellitus. Inclusion criteria included: (a) having been diagnosed with one or more of the conditions; (b) being able to read, understand and answer written questionnaires; (c) being fluent in English and (d) being able to provide written informed consent. Patients were involved in the design and pilot study of the scale.

**Results** A total sample of 577 people with an age range of 37–97 years ( $98 \pm 9.65$ ) were recruited. Internal consistency of the total 26-item LwLTCs scale score was excellent (ordinal  $\alpha=0.90$ ) but confirmatory factor analysis showed better fit indices (Normed Fit Index=0.96; standardised root mean square residual=0.051; Goodness of Fit Index=0.98) for a 20-item LwLTCs scale.

**Conclusions** A shorter version of the LwLTCs scale, with just 20 items and with excellent psychometric properties, is recommended. Having a short scale is key when considering the implementation of the scale in clinical practice to develop person-centred pathways and more comprehensive care plans.

## INTRODUCTION

Approximately 15.4 million people in the UK live with one long-term condition (LTC).<sup>1</sup> Due to an ageing population and increased diagnosis, it is expected to increase to 18 million by 2025.<sup>1</sup> Currently, the prevalence of LTC accounts for 16% of those under 40 and 58% of those over 60 years.<sup>2</sup>

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This validation study used an observational and cross-sectional design.
- ⇒ The sample size is a strength considering the challenge of recruiting these populations.
- ⇒ The sample represented a heterogeneous population, with patients from different sectors.
- ⇒ Most psychometric properties, including confirmatory factor analysis, were analysed.
- ⇒ Almost all participants were white British over 40, which could limit the generalisability.

Major contributors to these LTC include rheumatoid and osteoarthritis (9.1 million),<sup>3</sup> type 2 diabetes mellitus (T2DM) (3.8 million),<sup>4</sup> chronic kidney disease (CKD) (3 million),<sup>5</sup> chronic obstructive pulmonary disease (COPD) (1.2 million),<sup>6</sup> chronic heart failure (CHF) (580 000)<sup>7</sup> and Parkinson's disease (PD) (1 270 000 million).<sup>8</sup> With many LTCs underdiagnosed, the accurate morbidity rate is likely to be somewhat higher.<sup>9</sup> The cost to the National Health System is estimated to be between £1.4 and £10.2 billion per condition per year.<sup>9</sup>

Living with one or more than one LTCs has multiple complex implications, not only due to the medical consequences of the conditions but also to the people's ability to cope with and manage demands of daily living.<sup>10 11</sup> Living with multiple LTCs increases mortality and reduces quality of life and well-being.<sup>11 12</sup> People with LTCs have more difficulties with everyday activities, reduced ability to manage symptoms effectively and higher risks of disability and premature death.<sup>13</sup> LTCs involve psychosocial, environmental, economic and spiritual needs, which require support from health and social care services.<sup>9 13</sup>

In this regard, healthcare and policy is shifting focus from the illness to the person's needs and how he/she lives with and responds

to the illness.<sup>14 15</sup> More concretely, the phenomena 'living with an LTC' gains a meaning that goes beyond the biomedical management of the condition, integrating the whole psychosocial individual experience of the process.<sup>10 16</sup> Based on our previous research,<sup>10 17</sup> living with an LTC has been defined as a complex, dynamic, cyclic and multidimensional process that involves key elements, namely acceptance, coping, self-management, integration and adjustment. Accepting an LTC implies the absence of feelings of denial or anger, where the person acknowledges and assumes the fact that they have an LTC.<sup>10</sup> Coping refers to the process of learning to face the LTC and implementing different strategies to deal with the disease.<sup>10</sup> Self-management refers to having some knowledge about the LTC itself, adhering to a plan and actively participating in the decision-making that the illness involves.<sup>10</sup> Finally, integrating the LTC implies making changes in lifestyle to search for a new normal and adjusting entails a progressive process of the transformation of the person's self-identity, as the LTC also forms part of it.<sup>10</sup> Evidence also identified that the experience of living with LTCs (LwLTCs) is unique for each person, influenced by factors such as previous life experiences, personality types, values and beliefs, and coping skills for patients and family, affecting their quality of life.<sup>9 13</sup> This supports the fact that there are important parallels between different LTCs that could result in common care pathways and interventions, also applied to the management of multiple LTCs.

In order to plan individualised, comprehensive and targeted interventions to improve the experience of living with an LTC, an effective measure of the individual experience is needed.<sup>10 17</sup> To cover this need, the LwLTCs scale was developed within an international Spanish-speaking population.<sup>18</sup> Currently, the scale has been translated and piloted in English-speaking population LwLTCs naming the scale LwLTCs scale.<sup>19</sup> Preliminary results are waiting to confirm the satisfactory and promising results identified in the pilot study.<sup>19</sup> Moreover, because LwLTCs scale is not limited to an LTC, this study could show the extent to which it reflects the experience of living with one or more than one LTCs.

Therefore, the aim of this study is to present the psychometric properties of the LwLTCs scale in an English-speaking population of people living with different LTCs, such as arthritis, COPD, CHD, PD, CKD or T2DM, and discuss the clinical implications of its use.

## METHODS

### Design

An observational and cross-sectional study (one point-in-time evaluation, with test-retest) was conducted to validate the English version of the LwLTCs scale. This was the most suitable design for validation studies as the researcher was an observer and the data collection took place at predetermined points of time.<sup>20</sup>

### Patients

The following inclusion and exclusion criteria were applied during participant recruitment: (a) having been diagnosed with one or more of the following conditions by a general practitioner (GP) or consultant: arthritis, COPD, CHD, PD, CKD, T2DM; (b) any duration of the condition; (c) being able to read, understand and answer written questionnaires; (d) being fluent in English and (e) being able to provide written informed consent. The exclusion criteria were to present cognitive deterioration and/or psychiatric disorders or any other disorder that could interfere with or impede the reliability of the assessment of LTC manifestations or objectives of the study.

### Sampling and sample size

Consecutive cases sampling was applied to participant identification.<sup>21</sup> The sample size was based on the consideration of confirmatory factor analysis (CFA) and convergent validity. Based on high communality, 5–6 factors and 4–5 variables per factor,<sup>18</sup> a sample size of 260 per condition would be sufficient to determine an excellent-level (>0.98) criterion for the coefficient of congruence, aiming at a total 1650 participants. However, due to the COVID-19, recruitment was slightly modified and adjusted to the pandemic circumstances. Some GP services declared a lack of capacity or capability due to the further pressure the pandemic put on an already fragile primary care system<sup>22</sup> and declined to participate. Also, social distance circumstances changed the data collection method from an intentioned face to face to email and post. There might be other reasons for not taking part in the research, such as having perspectives on the potential lack of short-term benefits and usefulness of the research in the middle of the COVID-19 pandemic, lack of digital literacy to complete and send data online, difficulties in accessing postservices or experiencing low mood and decreasing the motivation to participate.

For the test–retest reliability, a sample of 60 per condition was estimated, to calculate the intraclass correlation (ICC) to within  $\pm 0.1$  if ICC=0.8 and to within  $\pm 0.05$  if ICC=0.9. Therefore, up to 60 people per condition were asked to complete the LwLTCs scale twice to avoid drop-out.

### Patient and public involvement

Prior to this validation study, a group of patient and public involvement representatives, living with different LTCs, such as osteoarthritis, T2DM, CKD, COPD, CHF and PD and multimorbidity, was conducted in order to ask them and gather their feedback in relation to the project plan and the LwLTC Scale. Members of the PPI group were invited to attend a meeting at our research facility. Arrangements were made to ensure that all members were able to access this location easily. The research team was introduced, and a short presentation of the project was given. Study documentation was provided to the participants and discussion was facilitated by the research team. Participants were encouraged to assess the overall

LwLTCs scale and supporting questions regarding relevance, usefulness, appropriateness and to ensure that there was no misunderstanding. This also provided the opportunity to identify any potential barriers due to assumed health literacy within the scale. Following this, views were collated and adjustments to the scale were made, this was then reviewed by randomly selected participants of the PPI group who then approved the changes. The PPI event was totally voluntary and without economic remuneration.

## Assessments

Sociodemographic data, such as age, gender, ethnicity and educational level, and data related to the age of diagnosis, current treatment and surgery for the LTCs, were collected. In addition, considering our previous findings of the elements that influence the process of living with an LTC<sup>11 23</sup> several validated outcome measures were used. It was estimated that the completion of all the outcome measures could take an average of 40 min per participant (as in the original study).<sup>18</sup>

The Living with Chronic Illness Scale is the only available tool in clinical practice and research to measure how people live with an LTC holistically, focusing on the person and not the disease.<sup>19</sup> It is a 26-item scale with five domains: (1) acceptance (four items), (2) coping (seven items), (3) self-management (four items), (4) integration (five items) and (5) adjustment (six items). All items are answered using a 5-point Likert scale from never or nothing (0) to always or a lot (4), except for domain 1-acceptance, which is reversely scored from never or nothing (4) to always or a lot (0). The scale has a total score value from 0 points, indicating negative living with the condition, to 104 points, reflecting positive living with the condition.<sup>18</sup> The principal variable of the study is 'living with an LTC' measured through the LwLTCs scale.

The LwLTCs scale was originally developed for Spanish-speaking population (in Spanish: Escala de convivencia con un proceso crónico EC-PC) and was developed based on empirical<sup>16 18</sup> and conceptual<sup>10</sup> studies carried out by international experts in the field of LTCs. Prior to this validation study, the scale was translated and cross-culturally adapted from the original LwLTCs scale (Spanish-language) to make it suitable for an English-speaking population.<sup>19</sup> The translation and cross-cultural adaptation process was conducted by a panel of four native English speaker experts. In addition, approval of the English version was sought from the original author of the LwLTC Scale in Spanish language.<sup>19</sup>

In addition to the LwLTCs scale, the following self-reported scales were used:

*Duke-UNC Functional Social Support Questionnaire (DUFSS).*<sup>23</sup>

It evaluates the social support of the patient from his/her perspective. It is an eight item that evaluates different dimensions of social support as confidant, affective and instrumental support. The score for each item varies from 1 (much less than I would like) to 5 (as much as I would

like). The Duke-UNC Functional Social Support Questionnaire (DUFSS) presented adequate psychometric properties, showing a Cronbach's alpha value of 0.9 and strong construct validity.<sup>23</sup>

*Satisfaction with Life Scale (SLS-6) (modified version).*<sup>24</sup>

It measures the degree of overall satisfaction with life (one item), regarding other five areas: physical, psychological well-being, social relations, leisure and financial situation. Each item scores from 0 (unsatisfied) to 10 (totally satisfied). The SLS-6 presented satisfactory psychometric properties, with a Cronbach's alpha of 0.8 and internal validity values ranging from 0.4 to 0.7.<sup>24</sup>

*WHO-Quality of life Scale (WHOQOL-BREF).*<sup>25</sup>

The WHO Quality of Life-BREF (WHOQOL-BREF) instrument was created by the WHO and comprises 26 items, which measure the following broad domains: physical health, psychological health, social relationships and environment. The WHOQOL-BREF is a shorter version of the original instrument that may be more convenient for this study in which several instruments will be completed. The WHOQOL-BREF is comprised by 24 items that evaluates physical health, psychological health, social relationships and environment. Item response options range from 1 (very dissatisfied) to 5 (very satisfied/very good quality of life). The WHOQOL-BREF presented adequate psychometric properties, showing a Cronbach's alpha value of 0.9.<sup>25</sup>

*Patient Global Impression of Severity (PGIS).*<sup>26</sup>

The Patient Global Impression of Severity (PGIS) is a self-reported generic scale that measures the patient's perception of health. It contains one question about the perception of the severity of the illness and six possible answers rating from 0 (not at all unwell) to 7 (among the most extremely unwell). The PGIS has excellent construct validity and has been widely used in studies of chronic diseases.<sup>26</sup>

## Data collection

Data collection was carried out between December 2021 and June 2022 across the UK via primary care surgeries and voluntary organisations, such as Parkinson's UK, Diabetes UK or Asthma UK. Sites were recruited with the assistance of local clinical research networks. It is important to mention that data collection was conducted during the COVID-19 pandemic. Therefore, due to COVID-19 lockdown and already-known restrictions, face-to-face collection of data was no longer an option.

Potential participants were identified by members of the primary care site using National Health Service (NHS) clinical databases (EMIS or SystemOne). These databases contain general information regarding the patient's condition. Those who met initial inclusion criteria were listed and checked individually by a GP or research nurse at the site to ensure that the patient was not at the end of life or in cognitive decline; if so, they were excluded. A letter of invitation to participate in the study was sent to those participants meeting the inclusion criteria, via the clinical team using Docmail, which is a



confidential mass mailing service approved by the NHS. Interested participants contacted the research team at the (blinded information) by a dedicated email address or phone line. Eligibility was checked and a patient information sheet was sent by post or email, followed by a consent form and questionnaires in accordance with ethical approval. Completed documents were returned to the research team by post using a freepost address or email. Two research team members checked the answers and participants were contacted again, via email or telephone and a maximum of two times, if there were missing data to obtain the information. Confidentiality was maintained by assigning participant numbers and storing patient identifiable information securely according to ethical guidelines. All questionnaires were checked for completeness and then a £10 thank you voucher was sent to the participants after completion.

### Data analysis

The data have been cleaned, formatted and analysed in SPSS (IBM Corp. Released 2021. IBM SPSS Statistics for Windows, V.28.0., IBM), SAS V.9.4 (SAS Institute). Descriptive analyses (central tendency measures, proportions) were used to analyse sociodemographic characteristics of the sample and also LTCs-related characteristics. The Consensus-based Standards for the selection of health Measurement Instruments<sup>27</sup> definition of the measurement properties was used in the following psychometric properties:

Data quality and acceptability was considered satisfactory if missing data was <5%.<sup>28</sup> Floor and ceiling effect were deemed acceptable if they were <15%<sup>29</sup> and the skewness was expected between -1 and +1.<sup>30</sup>

Internal consistency is the degree of inter-relatedness among the times.<sup>27</sup> Polychoric inter-item correlations and ordinal alpha measures were used to assess internal consistency<sup>31</sup> with alpha values higher than 0.70 considered good to excellent internal consistency.<sup>32</sup>

- CFA tests whether the data fit a priori hypothesised factor structure.<sup>33</sup> This was used to corroborate the original five domains structure of the LwLTCs scale. As the LwLTCs domains and total scores were not normally distributed, the unweighted least square estimation approach was used to estimate the parameters for the CFA models.<sup>34 35</sup> Fit indices of  $0.97 \leq \text{NFI}$  (=Bentler-Bonett Normed Fit Index)  $\leq 1$ ,  $0 < \text{SRMR}$  (=standardised root mean square residual)  $< 0.05$ ,  $0.95 \leq \text{GFI}$  (Goodness of Fit Index)  $\leq 1$  indicate a perfect fit, while fit indices of  $0.95 \leq \text{NFI} \leq 0.97$ ,  $0.05 < \text{SRMR} < 0.08$ ,  $0.90 \leq \text{GFI} \leq 0.95$  indicates an acceptable fit.<sup>36</sup>

Reproducibility is defined as the ability of a PROM to measure change over time in the construct to be measured.<sup>27</sup> This was evaluated through a test-7-day-retest approach. To ensure reproducibility, the research team facilitated the rationale for and the process of conducting the retest by providing clear instructions in the participant information sheet and after completing the first assessment, and the retest was provided in the

participant's preferred administration method. A subset of 122 participants completed a second assessment of the LwLTCs scale within a timespan of 7–10 days after the baseline assessment. Agreement between the two ordinally distributed measurements from the same individual was explored using the Wilcoxon signed-rank test. Asymptomatic significance ( $* < 0.05$ ,  $** < 0.01$ ,  $*** < 0.001$ ) indicates a significant disagreement between the two measurements taken 7–10 days apart, and ICC (one way, random effect; criterion  $\geq 0.70$ ) for domains and total score.

Construct validity is the degree to which the content of the scale is an adequate reflection of the construct to be measured.<sup>27</sup> It was assessed with Spearman rank correlations by determining (1) convergent validity: a moderate ( $r_s \geq 0.35$ – $0.50$ ) or strong relationship ( $r_s > 0.50$ ) was hypothesised between the LwLTCs scale and similar constructs measured by DUFSS, SLS-6, and WHOQOL-BREF, (2) discriminant validity: a weak ( $r_s < 0.30$ ) association was hypothesised between LwLTCs scale and dissimilar constructs such as age, age onset LTC, duration of LTC and PGIS.

Internal validity is understood as the intercorrelations between domains of the scale.<sup>27</sup> In this study, the LwLTCs scale domains (standard,  $r_s = 0.30$ – $0.70$ )<sup>30 36</sup> was determined.

Known-groups validity provides an adequate description of important characteristics of the subgroups, such as disease or demographic characteristics.<sup>27</sup> The following subgroups were analysed: gender, comorbidity, lifestyle changes, therapy or employment situation. Not significant differences were hypothesised between the total score of the LwLTCs scale and participants grouped by those subgroups. As the LwLTCs scale is not normally distributed, Kruskal-Wallis statistic and the Mann-Whitney U test were used for groups comparison.

## RESULTS

### Sample characteristics

A total of 577 participants living with at least one LTC, such as arthritis, COPD, CHD, PD and T2DM were recruited. The age range was 37–97 years, with a mean age of 98 (SD 9.65 years). 44.7% were female, 71.1% were married or in a civil partnership and just over half were living with the partner and/or spouse. The sample was mainly white British (97.7%) with limited representation from other ethnicity groups and retired (76.4%). Further sociodemographic information is shown in [table 1](#).

Regarding LTCs, although participants were recruited with the criteria of living with one LTC, more than half of the sample (70.1%) had more than one LTCs. The duration of the LTCs range was from 6 months to 76 years and on average, participants had lived with an LTCs for 11 years (SD 10.05 years). 87.7% of the sample were taking medication for the LTCs and just over half were experiencing a change in their lifestyle due to the LTCs. Further information regarding LTCs characteristics is shown in [table 1](#).

**Table 1** Sociodemographic and LTCs characteristics of the sample (n=577)

		N (%)
Gender	Male	310 (53.7)
	Female	258 (44.7)
	Prefer not to say	4 (0.7)
	Missing	5 (0.9)
Ethnicity	White	564 (97.7)
	Mixed or multiple ethnic groups	4 (0.7)
	Asian or Asian British	4 (0.7)
	Black, African, Caribbean or black British	1 (0.2)
	Other ethnic group	3 (0.5)
	Prefer not to day	1 (0.2)
	Missing	5 (0.9)
Marital status	Married	410 (71.1)
	Widowed	51 (8.8)
	Living with partner	29 (5.0)
	Single	35 (6.1)
	Separated/divorced	49 (8.5)
	Other	2 (0.3)
	Missing	5 (0.9)
Household composition	Alone	127 (22.0)
	With partner/spouse	367 (63.6)
	With partner/spouse+children/grandchildren	59 (10.2)
	With children/grandchildren	11 (1.9)
	With partner/spouse and hired carer	1 (0.2)
	Other relatives	4 (0.7)
	Other	8 (1.4)
	Missing	5 (0.9)
Education level	Primary school	4 (0.7)
	Secondary school	141 (24.4)
	Apprenticeship	29 (5.0)
	College	154 (26.7)
	University degree	139 (24.1)
	Postgraduate studies	88 (15.3)
	Doctorate	17 (2.9)
	Missing	5 (0.9)
Employment	Retired	441 (76.4)
	Employed (>40 hours)	29 (5.0)
	Employed (<40 hours)	63 (10.9)
	Looking for work	5 (0.9)
	Not employed and not looking for work	20 (3.5)
	Disabled/not able to work	19 (3.3)

Continued

**Table 1** Continued

		N (%)
Lifestyle changes	Yes	322 (55.8)
	No	247 (42.8)
Therapy	Yes	189 (32.8)
	No	379 (65.7)
Surgery	Yes	123 (21.3)
	No	448 (77.6)
Primary LTC	Arthritis	126 (21.8)
	Parkinson's disease	241 (41.8)
	Diabetes type II	70 (12.1)
	Chronic heart disease	78 (13.5)
	Chronic obstructive pulmonary disease	60 (10.4)
Other LTCs	None	196 (34.0)
	Arthritis	262 (45.4)
	Parkinson's disease	60 (10.4)
	Diabetes type II	1 (0.2)
	Chronic heart disease	1 (0.2)
	Only one LTC	59 (10.2)
LTCs characteristics		
Current age		Mean±SD (range) in years 68.0±9.27 (37–97)
Duration LTC		Mean+SD, median+mode (range) 11.0±10.05, 8.0, 4.0 (0.5–76)
.LTC, long term condition.		

### Data quality and acceptability

Results related to data quality showed that there were seven missing data (three in domain 2-coping, one in domain 3-self-management and three in domain 5-adjustment). Twenty-four of the 26-items included in the LwLTCs scale showed flooring/ceiling effects and were moderately (outside  $-0.5$  to  $+0.5$  range) to highly (outside the range  $-1$  to  $+1$ ) skewed. The participant scores for domain 4integration were also skewed. The Shapiro-Wilk tests showed that the total, domain and item scores of the English version of the LwLTCs were not normally distributed. Due to the presence of ceiling/flooring effects, skewness and significant Shapiro-Wilk tests, we decided to employ non-parametric statistics to test the validity of the LwLTCs scale.

### Internal consistency

Results related to internal consistency of the LwLTCs scale showed that ordinal alpha was 0.90 for the total scale and for the domains ranged between 0.68 (domain 3-self-management) and 0.87 (domain 1-acceptance).

**Table 2** Feasibility/acceptability, reliability and precision of the LwLTCs scale

	LwLTCs scale					
	Domain 1: acceptance	Domain 2: coping	Domain 3: self-management	Domain 4: integration	Domain 5: adjustment	LwLTCs total score
Data Quality (% fully computable data)	0	3	1	0	3	7
Floor effect (%)	1.2	0.9	0.9	0.7	0.9	0
Ceiling effect (%)	9	2.6	4.9	8.5	2.1	0
Skewness	-0.7	-0.5	-0.6	-1	0.1	-0.3
Ordinal alpha	0.87	0.80	0.68	0.72	0.85	0.90
Inter-item polychoric correlation	0.49–0.74	0.13–0.60	0.22–0.45	-0.09–0.69	0.19–0.70	–
Reproducibility (ICC)	0.81	0.82	0.75	0.73	0.77	0.86

.ICC, intraclass correlation; LwLTCs, living with long term conditions.

All intercorrelations between the LwLTCs scale domains ranged between 0.04 (domain 3-self-management) and 0.74 (domain 1-acceptance). See [table 2](#) for further information.

### Confirmatory factor analysis

The CFA did not show a good fit for the originally proposed 5-domain structure fitted to the 26 items (see online supplemental figure 1). The fit of the structure improved significantly if items 2, 5, 10, 16, 18 and 23 were to be removed and item 24 was reassigned to domain 4-integration. This final CFA model (see online supplemental figure 2) with 5 domains and 20 items showed good fit indices (NFI=0.96; SRMR=0.051; GFI=0.98).

### Reproducibility

Reproducibility was determined on the 7-day apart consecutive measurements of 122 participants living with arthritis (n=27), COPD (n=8), CHD (n=20), PD (n=44), CKD (n=20) and T2DM (n=18). The ICC for the total scale was 0.86 and for all domains was over 0.75 except for domain 4-integration (see [table 2](#)). For items, Cohen's kappa ranged between 0.31 (item 8) and 0.58 (item 6). As the items, domains and total score of the LwLTCs scale are not normally distributed, Wilcoxon signed-rank test was applied to determine the level of agreement between the baseline LwLTCs measurement and the second LwLTCs assessment 7–10 days later. Findings indicate that there are no significant differences between baseline and second assessment measurement for most of the items, except for items 8, 10, 11, 12 and 21. The significant differences in these items also affect the reproducibility of domain 2-coping, domain 3-self management and the LwLTCs total score.

### Construct validity

In agreement with our hypothesis, the results in [table 3](#) showed that the LwLTCs scale strongly correlated with SLS-6 ( $r_s=0.58$ ) and WHOQOL-BREF ( $r_s=0.50$ ) and moderately correlated with DUFSS ( $r_s=0.43$ ). In addition, weak or negligible correlations were identified between LwLTCs scale and clinical characteristics such as the

patient impression of LTCs severity (PGIS) or duration of LTCs (see [table 3](#)).

According to internal validity analysis, correlation values between LwLTCs domains ranged from 0.31 to 0.51, except for domain 1-acceptance that showed low correlations with domain 2-coping, domain 3-self-management and domain 5-adaptation. See [table 3](#) for further detail.

As shown in [table 4](#), in agreement with our hypothesis, the total score of known-group validity analysis showed no significant differences were identified for gender, comorbidity, lifestyle changes or therapy. However, significant difference was identified for the LwLTCs scale on employment situation ( $p=-0.017$ ). A summary of the key findings is shown in [table 5](#).

## DISCUSSION

This is the first validation study of the LwLTCs scale in an English-speaking population living with different LTCs. Until now, the LwLTC Scale has only been available in Spanish.<sup>19</sup> Hence, this study covers an important gap related to reliable and valid person-centred tools to evaluate the process of LwLTCs in English-speaking countries.

The internal consistency of the LwLTCs scale was excellent (0.90) both overall and for each domain. However, some of the inter-item polychoric correlations indicate that it would be better to remove certain items due to low correlations (eg, items 5, 12) and overlaps (eg, items 10/11, 16/17, 23/24) showing redundancy in the content of the items.<sup>37</sup> These findings completely aligned with the CFA findings of this study. Particularly, the CFA did not support the original structure of the scale.<sup>10</sup> Findings showed that there is a considerable amount of overlap among certain items (items 2/4; 10/11; 16/17; 23/24) and certain items do not fit well within the construct being measured (items 5 and 18). Hence, a 5-domain and 20 item version worked better than the 26-item original version. These findings align with other validation results<sup>19 38</sup> conducted in the Spanish version of the scale for people living with different LTCs. For instance, the CFA conducted in Spanish-speaking population living

**Table 3** Convergent validity and internal validity of the LwLTCs scale

		LwLTCs scale					
		Domain 1: acceptance	Domain 2: coping	Domain 3: self-management	Domain 4: integration	Domain 5: adjustment	Total score
Convergent validity	Age	0.18***	0.04	-0.004	0.12**	0.04	0.09*
	Age-onset LTC	0.11**	0.05	0.06	0.06	-0.03	0.06
	Duration LTC	0.04	-0.06	-0.03	0.02	0.02	-0.01
	WHOQOL-Physical health	0.56***	0.20***	0.13**	0.54***	0.32***	0.44***
	WHOQOL-Psychological	0.57***	0.41***	0.29***	0.65***	0.46***	0.64***
	WHOQOL-Social relationships	0.28***	0.35***	0.23***	0.42***	0.36***	0.45***
	WHOQOL-Environment	0.46***	0.33***	0.34***	0.57***	0.35***	0.53***
	WHOQOL-Overall QOL	0.48***	0.31***	0.19***	0.54***	0.38***	0.50***
	DUFSS	0.37***	0.36***	0.19***	0.42***	0.26***	0.43***
	Satisfaction With Life	0.54***	0.36***	0.18***	0.58***	0.48***	0.58***
	Satisfaction-physical health	0.53***	0.30***	0.18***	0.54***	0.43***	0.54***
	Satisfaction-well-being	0.49***	0.31***	0.20***	0.53***	0.37***	0.52***
	Satisfaction-social relations	0.42***	0.34***	0.18***	0.47***	0.32***	0.47***
	Satisfaction-leisure	0.49***	0.31***	0.17***	0.57***	0.41***	0.53***
	Satisfaction-financial situation	0.29***	0.19***	0.25***	0.35***	0.23***	0.34***
	Patient impression illness severity	-0.44***	-0.10*	-0.09*	-0.37***	-0.25***	-0.32***
Internal validity	Coping	-0.18*	-	-	-	-	-
	Self-management	-0.08*	0.44***	-	-	-	-
	Integration	0.47***	0.43***	0.41***	-	-	-
	Adjustment	0.28***	0.51***	0.31***	0.48***	-	-

Spearman rank correlations: \* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$ .

DUFSS, Duke-UNC Functional Social Support Questionnaire; LTC, long term condition; LwLTC, living with long term conditions; QOL, quality of life; WHOQOL, WHO Quality of Life.

with T2DM also showed that a shorter and adjusted version of the scale presented better fit indices.<sup>38</sup>

The reproducibility results showed that some participants scored quite different (lower) at the second assessment for some items and the whole LwLTCs scale. These results are in line with the CFA results, indicating the removal of certain items will improve the validity and reliability of the LwLTCs scale. However, reproducibility results from this study should be interpreted with caution because it was not assessed during the second data collection if personal circumstances (ie, change in economic status, medication for the condition or familiar issues) had changed for the participants that could justify the differences between the data measurements. One of the reasons behind these results could be the physical and mental health alterations that the COVID-19 pandemic might have generated in participants' daily lives. Hence, further analyses are recommended to identify if the LwLTCs scale captures how the person lives with LTCs repeatedly under the same circumstances.

Regarding convergent validity, as hypothesised, the process of living with an LTC presents moderate or strong relationship with social support, satisfaction with life and quality of life. Similarly, weak or negligible correlations

were identified between LwLTCs scale and clinical characteristics, such as patient impression of LTC severity or duration of LTCs. These findings were also identified in the Spanish-speaking validation study among multiple LTCs,<sup>19</sup> such as DM2,<sup>37</sup> PD,<sup>18</sup> COPD,<sup>39</sup> CHF<sup>40</sup> or arthritis.<sup>41</sup> Once again, this study corroborates the comprehensive approach needed when assessing the daily living of people with LTCs, focusing on the person and not the disease. Therefore, social support, satisfaction with life and quality of life assessments should be addressed through collaboration between the healthcare and social system. Particularly, the LwLTCs scale could be used as a complement to conventional generic health-related quality of life measures or other existing medical records platforms available in the NHS. This could constitute a basis for evaluation where interventions may affect both health and social care outcomes, including mental health and well-being and in comparing outcomes and resource allocation across different areas of the public sector.<sup>42</sup>

The internal validity for LwLTCs scale domains was good to excellent, except for domain 1: acceptance, with correlation coefficients very low with the rest of the domains. This result is consistent with previous validation studies<sup>18 19</sup> and conceptual work,<sup>10</sup> showing that accepting



**Table 4** Known-group validity

Categories	LwLTCs scale total	P value
Sex		0.49
Men	66.6 (15.2)	
Women	65.4 (15.2)	
Employment		0.017
Employed	64.3 (14.5)	
Unemployed	58.2 (17.4)	
Retired/disabled	66.8 (15)	
Comorbidities		0.76
None	66.1 (15)	
Arthritis	66.1 (15.3)	
Parkinson's disease	67.5 (15.3)	
Lifestyle changes		0.85
Yes	66.0 (14.2)	
No	65.9 (15.9)	
Therapy		0.12
Yes	64.7 (14.6)	
No	66.4 (15.3)	

LwLTCs, living with long term conditions.

the condition is always the first step to achieve a positive living. Hence, only when the person has accepted and assumed his/her illness can he or she move on to the other domains such as coping or self-management.<sup>10 43</sup> Therefore, according to the poor correlation that domain

1-acceptance showed with other domains of the LwLTCs scale and previous validation studies, this finding was expected because acceptance is considered an internal, illness-independent process through which the person recognises and accepts the reality.<sup>42 44</sup>

LwLTCs scale demonstrated satisfactory know-group validity, yielding not significant differences for gender, comorbidity, lifestyle changes or therapy. This means that the LwLTCs scale equally evaluates the degree of living with an LTC in all individuals independently of gender, comorbidity, lifestyle changes or therapy. Hence, this shows that the LwLTCs scale could be used with a diverse LTCs population without discriminating their gender, lifestyle or therapy, preventing inequalities. Nevertheless, surprisingly significant differences were identified for employment situation. This means that the LwLTCs scale could capture differences among people with different employment situations. However, among the sample very few participants were unemployed which does not cover other employment situations. Hence, to identify if the LwLTCs scale captures the differences among people with different employment situations or not, future research is recommended.

Having a short scale, with just 20 items and with excellent psychometric properties, is key when considering the implementation of the scale in clinical practice in primary care settings with short time consultations and staff shortage. Using the LwLTCs in primary care could result in more optimal healthcare utilisation without sacrificing quality of life and economic costs because it could ensure more effective risk stratification and

**Table 5** Summary of the key findings

Psychometric property	Established criteria	Findings—LwLTCs scale score
Data quality and acceptability	<ul style="list-style-type: none"> <li>▶ Missing data &lt;5%</li> <li>▶ Floor and ceiling effect &lt;15%</li> <li>▶ Skewness -1 to +1</li> </ul>	<ul style="list-style-type: none"> <li>▶ Missing data 1.2% (n=7)</li> <li>▶ Floor and ceiling effect=0%</li> <li>▶ Skewness=-0.3</li> </ul>
Internal consistency	▶ Ordinal $\alpha \geq 0.70$	▶ Ordinal $\alpha = 0.90$
Confirmatory factor analysis	▶ Originally proposed 5-domain structure fitted to the 26 items	▶ Good fit with 5 domains and 20 items (NFI=0.96; SRMR=0.051; GFI=0.98)
Reproducibility	▶ Intraclass correlation coefficient $\geq 0.70$	▶ Intraclass correlation coefficient=0.86
Construct validity	<ul style="list-style-type: none"> <li>▶ Strong (<math>r_s &gt; 0.50</math>) or moderate (<math>r_s \geq 0.35-0.50</math>) relationship was hypothesised between the total score of the LwLTCs scale and DUFSS, SLS-6 and WHOQOL-BREF</li> <li>▶ Weak (<math>r_s &lt; 0.30</math>) relationship was hypothesised between the total score of the LwLTCs scale and age of the person, age onset LTC, duration of LTC and PGIS</li> </ul>	<ul style="list-style-type: none"> <li>▶ Strong correlations were identified with SLS-6 (<math>r_s = 0.58</math>) and WHOQOL-BREF (<math>r_s = 0.50</math>) and moderate correlations with DUFSS (<math>r_s = 0.43</math>)</li> <li>▶ Weak or negligible correlations were identified with PGIS (<math>r_s = -0.32</math>), duration of LTC (<math>r_s = -0.01</math>), age onset LTC (<math>r_s = 0.06</math>) and age of the person (<math>r_s = 0.09</math>)</li> </ul>
Internal validity	▶ $r_s = 0.30-0.70$	▶ $r_s = 0.31-0.51$
Know-group validity	▶ Not significant differences were hypothesised between the total score of the LwLTCs scale and gender, comorbidity, lifestyle changes, therapy or employment situation	▶ Significant differences for employment situation ( $p = -0.017$ )

DUFSS, Duke-UNC Functional Social Support Questionnaire; GFI, Goodness of Fit Index; LTC, long term condition; LwLTCs, living with long term conditions; NFI, Normed Fit Index; PGIS, Patient Global Impression of Severity; SLS-6, Satisfaction with Life Scale; SRMR, standardised root mean square residual; WHOQOL-BREF, WHO Quality of Life Scale.



the early identification of people with higher needs for more complex care coordination and high or low risk for poor self-management. Specifically, the LwLTCs scale could facilitate the implementation of NICE pathways and recommendations for LTCs.<sup>45</sup> Particularly, a more comprehensive care plan, directed referral to specialists or other resources and support groups in the community, regular monitoring and points of contact of support<sup>45</sup> could be ensured based on the results of the LwLTCs scale assessment. Finally, the LwLTCs scale is very relevant to the quality requirements of the National Services framework for LTCs<sup>46</sup> especially when it comes to the assessment of personal care and support to tackle physical, emotional, spiritual and social needs, improving connections between health and social care.

### Strengths and limitations

This is an innovative and unique validation study of the LwLTCs scale among English-speaking population LwLTCs. The findings of this study align well with findings identified in Spanish-speaking population, leading to a recommendation for a shortened version of the scale with excellent psychometric properties. Finally, although the negative impact of COVID-19, the project kept running successfully.

Regarding the limitations, sample characteristics could limit the generalisability of the findings of this study. First, of the 577 participants included in this study 241 had PD. Second, most participants in the current study were over 40 years old. Hence, results are not generalisable to younger adults LwLTCs on working age. Third, almost all participants in this study were white British. Therefore, in order to overcome this sampling limitation, the recruitment efforts of future validation studies of the LwLTCs scale should focus on inclusion of young adult population, people living with multiple different LTCs, and ethnic representative groups, such as black or Asian. Finally, we cannot ignore the impact that the COVID-19 pandemic had on this project. Recruitment process was adapted to social distancing circumstances and data collection was conducted smoothly although the impact of the change in circumstances for people with LTCs could have caused the observed differences between the Spanish and the English validation studies. Also, due to COVID-19 pandemic, initially calculated sample size was not reached, having a smaller sample size. This could have interfered with the results of the CFA.

### CONCLUSIONS

This paper provides the first psychometric analysis of the LwLTCs scale in English-speaking population among people living with different LTCs. A shorter version of the LwLTCs scale, maintaining the 5 domains but just with 20 items is recommended. This shorter version of the scale, with excellent psychometric properties, is ready to be used in clinical practice to facilitate the implementation of person-centred care pathways and more effective

referrals. Prior to the full implementation trial, a feasibility testing using the 20 items version of the scale is recommended.

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