



RESEARCH ARTICLE

Living with Long term condition Scale: A pilot validation study of a new person centred tool in the UK

Leire Ambrosio^{1,2}  | Kelly Hislop-Lennie¹ | Hannah Barker² | David Culliford^{1,2} | Mari Carmen Portillo^{1,2} 

¹School of Health Sciences, University of Southampton, Hampshire, UK

²NIHR Applied Research Collaboration, Wessex University of Southampton, Hampshire, UK

Correspondence

Mari Carmen Portillo, FEANS, PhD, MSc, RN, NIHR Applied Research Collaboration Wessex, School of Health Sciences, University of Southampton, Building 67, University Road, SO171BJ Southampton, United Kingdom.
Email: M.C.Portillo-Vega@soton.ac.uk

Funding information

This study has been funded by the NIHR Applied Research Collaboration Wessex Programme.

Abstract

Aim: To cross-culturally adapt and determine the preliminary psychometric properties of the English version of the LwLTC Scale in people living with long-term conditions in the UK.

Design: Cross-cultural adaptation and cross-sectional study.

Methods: Forty-nine patients with five long-term conditions were included in the pilot study. Patients completed the English version of the LwLTC Scale and a *bespoke* questionnaire related to the scale. Feasibility/acceptability, internal consistency and construct validity were analysed.

Results: 59.2% of participants were female, with an average age of 65.9 ($SD = 12.30$). Cronbach's alpha coefficient ranged between 0.50 and 0.84. Content validity showed that the English version of the LwLTC Scale was useful even negative items were identified.

Conclusion: These preliminary psychometric properties are satisfactory and promising. Further psychometric analyses are needed to verify them in a larger and more representative sample size during the main validation study, which is now in process.

KEYWORDS

cross-cultural adaptation, instruments, living with, long term condition, patient, person centred, pilot study

1 | INTRODUCTION

Advances in public health, together with improvements in clinical interventions, have led to an increase in life expectancy in almost all regions of the world. This has resulted in major demographic changes, and this is expected to continue. The continuous ageing process of global populations is resulting in a significant growth in the number of people with long-term conditions (LTCs) (NHS, 2019). LTC is defined as a chronic condition for which there is currently no cure but could be managed and/or controlled by medication and/or

other therapies (Department of Health, 2012). Nowadays, LTCs are responsible for 41 million of deaths each year, the equivalent for the 71% of all deaths worldwide (World Health Organization (WHO), 2020). More concretely, in the United Kingdom LTCs affect approximately 15.4 million people and is expected to rise to 18 million by 2025 (Department of Health, 2012). It is undeniable that living with LTCs has become one of the major health challenges worldwide (World Health Organization (WHO), 2020). In terms of costs, managing LTCs accounts for 70% of the total health and social care expenditure in the NHS (Department of Health, 2012). Moreover, people

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2021 The Authors. *Nursing Open* published by John Wiley & Sons Ltd.

living with one or more LTCs have a higher risk of mortality and lower quality of life and well-being, affecting their families and caregivers too (NHS, 2019; World Health Organization (WHO), 2020).

Nowadays, health care and policy attention are changing the focus from the illness to the person and how he/she lives with a LTC (World Health Organization (WHO), 2020). In this regard, the phenomena "living with an LTC" has gained a meaning that goes beyond the biomedical features, integrating the psychosocial and spiritual individual experience (Ambrosio, Senosiain, et al., 2015; Department of Health, 2012). Living with one or more LTCs is understood as a complex and unique process that involves key elements, namely Acceptance, Coping, Self-management, Integration and Adjustment (Ambrosio et al., 2016; Ambrosio, Senosiain, et al., 2015; Navarta-Sánchez et al., 2017; Portillo et al., 2012; Zaragoza et al., 2014). Living with one or more LTCs is a personal experience that can be influenced by several factors, such as previous life experiences, personality types, values and beliefs, and social support (Ambrosio, Senosiain, et al., 2015; Portillo et al., 2012; Zaragoza et al., 2014). Therefore, considering personal factors related with the person's and his/her daily living is paramount to achieve a positive living and promoting a better quality of life and psychosocial well-being (Ambrosio et al., 2019; Ambrosio, Senosiain, et al., 2015; Haahr et al., 2010; Kang & Ellis-Hill, 2015; May et al., 2016; Navarta-Sanchez et al., 2016, 2017; Prizer & Browner, 2012).

2 | BACKGROUND

Existing care guidelines and pathways reflect the complexity of the process of living with LTCs and put people at the centre of the decision-making process (Lim et al., 2017; Navarta-Sanchez et al., 2016; Pemberton, 2014). However, the design of these care pathways is limited by the lack of comprehensive assessment tools that clearly represent personal needs and daily routines and life with LTCs (Kang & Ellis-Hill, 2015; Navarta-Sánchez et al., 2017; Prizer & Browner, 2012; Soundy et al., 2014). Most relevant available instruments measure specific aspects related to LTCs (social support, symptoms, severity of conditions, coping skills) or outcomes of the process of living with LTCs (quality of life, satisfaction with life) leading to a fragmentation of the assessment of needs and consequently, care plans (Ambrosio & Portillo, 2018; Martinez-Martin et al., 2014; Mendes, 2015). Tools such as the Long-Term Conditions Questionnaire (Potter et al., 2017), the Survey on living with chronic diseases in Canada (Public Health Agency of Canada, 2009) or the Minnesota Living with heart failure questionnaire (Rector et al., 1987) are measures that have been developed potentially to evaluate the process of living with an LTC from the patient perspective. However, these instruments do not accurately evaluate the process of living with an LTC because they assess other related constructs like quality of life (Ambrosio et al., 2020; Ambrosio & Portillo, 2018). The Long-Term Conditions Questionnaire (Potter et al., 2017) is the only measure that actually evaluates how people live with/manage their LTCs. This measure is a patient-reported outcome tool that has been

validated in a wide and representative sample of patients living with LTCs in three regions of England (Potter et al., 2017). Despite the potential relevance of the Long-Term Conditions Questionnaire in clinical practice and research, there is no clarity about the interpretation and utility of its general punctuation for referral processes and implementation of care pathways and the omission of items to assess the levels of acceptance of LTCs (Ambrosio, Senosiain, et al., 2015), which are essential in this process.

Based on this to our knowledge, the Living with Long term condition Scale (LwLTC Scale) could become the only available person-centred tool that captures the individual perception of daily living with LTCs (Ambrosio & Portillo, 2018) cross-culturally. Until now, the LwLTC Scale has only been available in Spanish and has been successfully validated in several prototypical LTCs, such as Parkinson's disease, chronic heart failure, chronic obstructive pulmonary disease, diabetes mellitus type 2, rheumatoid arthritis and hypertension (Ambrosio et al., 2015, 2016, 2020). However, the English version has not been developed yet leaving an important gap related to reliable and valid person-centred tools to evaluate the process of living with LTCs in English-speaking countries.

Based on this, the aim of this study is to produce an English version of the LwLTC Scale and establish if it can be useful and applicable to an English-speaking population with LTCs in the UK. More concretely, two specific aims were proposed: a) to cross-culturally adapt the Spanish version of the LwLTC Scale to an English-speaking population and b) to determine the preliminary psychometric properties of the English version of the LwLTC Scale in a pilot study before the main validation.

3 | THE STUDY

3.1 | Design

A pilot observational and cross-sectional study was carried out in the Wessex Area of the UK.

3.2 | Methods

3.2.1 | Cross-cultural adaptation

The aim of this process was to translate and cross-culturally adapt the original LwLTC Scale (Spanish language) to make it suitable for an English-speaking population living with LTCs. According to international standardized protocols for cross-cultural adaptation (International Test Commission, 2010; Sousa & Rojjanasrirat, 2011; Wild et al., 2009) and after obtaining written permission from the original author of the LwLTC Scale, the translation and cross-cultural adaptation process were conducted by a panel of four experts. Those experts were native English speakers from different countries and ensured that the English version of the LwLTC Scale was acceptable for all English-speaking countries and not just for British English

speakers. In addition, approval of the English version was sought from the original author of the LwLTC Scale in Spanish language. The translation and cross-cultural adaptation process are described in Figure 1.

3.2.2 | Patient and Public involvement (PPI)

A group of PPI representatives including 8 people living with rheumatoid arthritis (RA), Parkinson's disease (PD), diabetes mellitus type 2 (DM2), chronic heart failure (CHF) and chronic obstructive pulmonary disease (COPD) and multimorbidity, in several cases, was organized in order to consult them and gather their feedback in relation to the project plan and the LwLTC Scale. The dynamic of the session followed thus a) presentation of the research team and the

project; b) material facilitation and brief period to review it; c) discussion in groups and in pairs about the material, regarding questions such as the relevance and usefulness of the scale in clinical practice and for their daily living, the appropriateness of the length, or misunderstanding items; d) summary of the main ideas; and e) further collaboration at a later stage in the project. The PPI event was totally voluntary and without economic remuneration.

3.2.3 | Setting, sampling and sample

A consecutive case sampling (Bowling, 2014; Peduzzi et al., 1996) was applied to participant identification in the community from the Wessex Area in England.

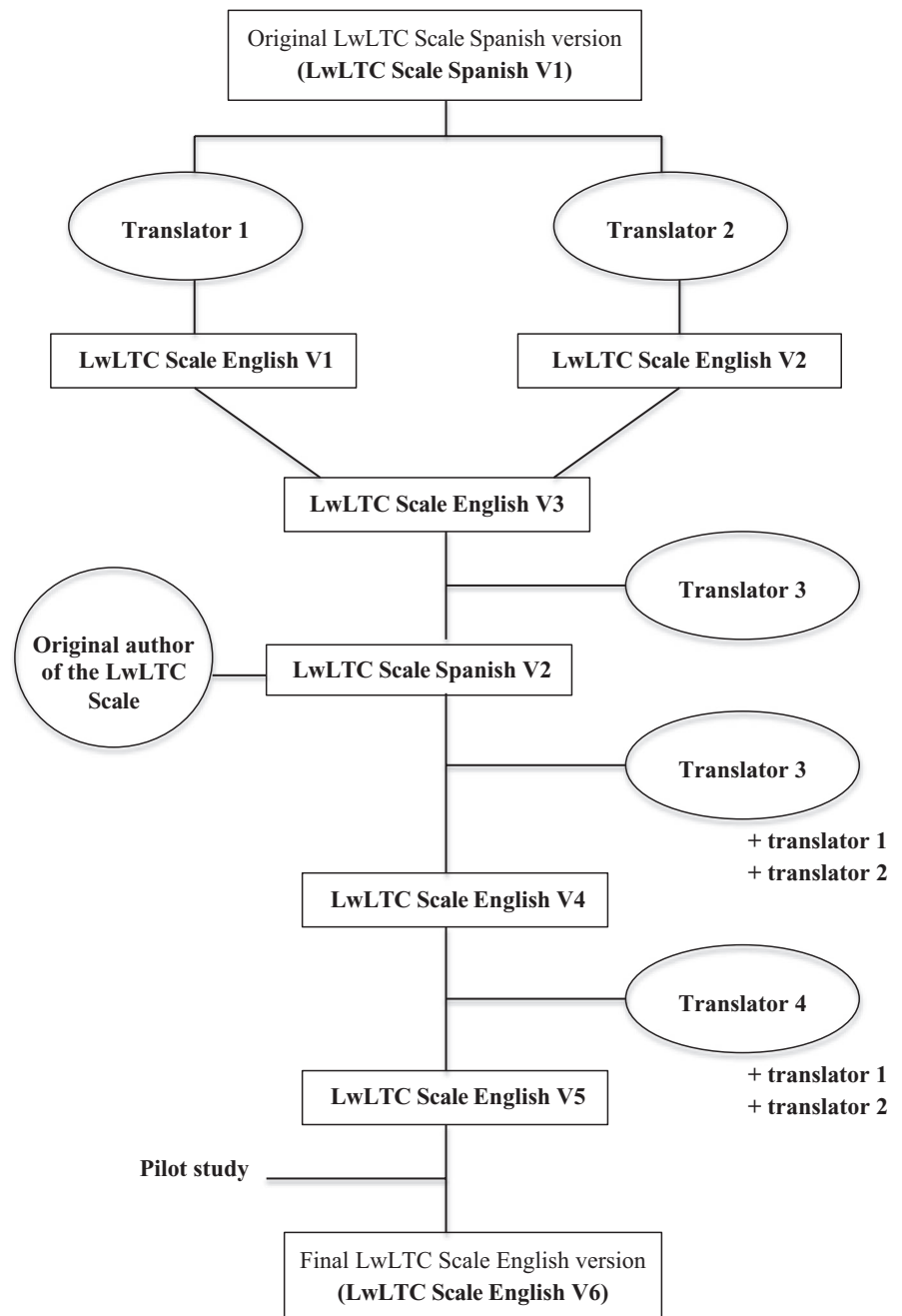


FIGURE 1 Translation and cross-cultural adaptation of the Living with Long term condition Scale (LwLTC Scale)

The sample was composed of people living with RA, PD, DM2, CHF and COPD that meet the following inclusion criteria: having been diagnosed with one or more of the LTC by a GP or consultant (RA, PD, DM2, CHF and COPD); being able to read, understand and answer written questionnaires; living in the community and not being hospitalized in moment of the study; being a native English speaker; and being able to provide written informed consent. Exclusion criteria were as follows: having cognitive deterioration and/or current psychiatric disorders, or any other disorder that could interfere with or impede the study, such as answering self-reported scales, and not meeting established inclusion criteria.

According to international criteria (Martinez-Martin & Frades Payo, 2006), a sample size of minimum five and a maximum of ten patients per condition was established. Thus, for this pilot study a sample size of 25–50 patients living with at least one of the LTCs was sought.

3.2.4 | Data collection

Mirroring previous validation studies of the LwLTC Scale with people with LTCs in Spanish-speaking populations (Ambrosio, Navarta-Sanchez, Meneses, et al., 2020; Ambrosio, Portillo, et al., 2015; Ambrosio et al., 2016), we planned this pilot study. Data collection was carried out between February and May 2020 through local branches of relevant voluntary organizations (Parkinson's UK, Diabetes.org, British Heart Foundation), community centres, church groups and social media like Facebook. To ensure reproducibility and homogeneity during the data collection of the pilot study, a protocol was established with the following steps: participants were self-selected to participate in the study, responding to an invitation available on different voluntary organization websites or meetings, as mentioned before. They were assessed by a member of the research team who decided if the participants were eligible or not according to established criteria. If the person was eligible, he/she was asked to attend a local venue (non-NHS) to meet with the research member. After giving pertinent verbal and written information, the participant was asked to sign the written informed consent form. After consenting to take part voluntarily, the participant completed all the questionnaires, which took an average of 40 min per participant.

COVID-19 pandemic impact on the procedures. UK Government shielding and lockdown measures were implemented during the data collection of this project. Therefore, we needed to introduce a new procedure for data collection that aligned to the lockdown and social distancing measures instructed by the UK Government and prioritized the safety and vulnerability of the participants. The new procedure for data collection was as follows: a) an email invitation was sent to potential participants; b) those interested in the study were asked to send an email to the project generic email address; c) a member of the research team related to this study, replied with a standard email asking to complete the electronic informed consent form and arranging an interview appointment. During the telephone

interview, the participant read their own questionnaires and then told the researcher their answers. The telephonic data collection took shorter time than face to face, with an average of 30 min per participant.

3.2.5 | Instruments

Socio-demographic data such as age, gender, marital status, ethnicity, employment, economical situation and educational level were collected. Also, LTC historic data were collected, including age at diagnosis, duration of LTC, treatment or surgery for LTC, and multimorbidity.

The LwLTC Scale is a self-reported measuring instrument to evaluate the complex process of living with LTCs with a person-centred approach (Ambrosio, Portillo, et al., 2015). It is a 26-item Scale grouped in five domains: 1—Acceptance (4 items), 2—Coping (7 items), 3—Self-management (4 items), 4—Integration (5 items) and 5—Adjustment (6 items). Items are scored on a 5-point Likert Scale ranging from 0 (never/nothing) to 4 (always/a lot), except for domain 1—Acceptance that ranges in the opposite direction (4: never/nothing to 0: always/a lot). Total score ranges from 0 (most negative living with PD) to 104 (most positive living with PD) (Ambrosio, Portillo, et al., 2015). The results from the first validation study in Spanish-speaking population living with Parkinson's disease showed satisfactory psychometric properties (Cronbach's alpha values ranged between 0.68 and 0.88 and internal validity correlations ranged from 0.46 to 0.78) (Ambrosio et al., 2016).

In addition to the scales and socio-demographic form described above, participants were asked to complete a *bespoke* questionnaire related to the adequacy and relevance of the LwLTC Scale and format aspects in the target population. This was used to understand the adequacy and relevance of the scale and format aspects in the target population.

3.2.6 | Data analysis

The aim of every pilot study is to replicate the formal validation study in a small sample size in order to identify necessary modifications (misunderstanding words, procedure problems, etc.) and consequently achieve an instrument that is as clear and concise as possible (DeVellis, 2012; Martinez-Martin & Frades Payo, 2006). In this sense, in order to have an orientation about the preliminary psychometric properties of the English LwLTC Scale version, the following statistical analysis were conducted:

Descriptive statistics (central tendency measures, proportions) were used to determine the socio-demographic and clinical characteristics of the participants. Main data were ordinal or did not fit normal distribution; therefore, non-parametric statistics were used. In order, the following psychometric attributes were tested:

Feasibility and acceptability. Quality of data was considered satisfactory if 95% of the data were computable. The limit for missing

TABLE 1 Socio-demographic characteristics of the total sample and historical data of the long-term conditions ($n = 49$)

	Total sample		RA		PD		DM2		CHF		COPD	
	N	%	N	%	N	%	N	%	N	%	N	%
Sex												
Male	20	40.8	3	27.3	5	45.5	7	63.6	2	40	3	40.8
Female	29	59.2	8	72.7	6	54.5	4	36.4	3	60	8	59.2
Marital status												
Married	35	71.4	7	63.6	10	90.9	8	72.7	4	80	6	54.5
Single	5	10.2	3	27.3	0	0	0	0	0	0	2	18.2
Widowed	3	6.1	1	9.1	0	0	0	0	0	0	2	18.2
Other	6	12.2	0	0	1	9.1	3	27.3	1	20	1	9.1
Education level												
Basic—primary studies	18	36.8	5	45.5	4	36.4	6	54.5	0	0	3	27.3
Secondary studies	14	28.6	3	27.3	3	27.3	2	18.2	1	20	5	45.5
University—postgraduate studies	17	24.7	3	27.3	4	36.4	3	27.3	4	80	3	27.3
Employment												
Employed	11	22.4	5	45.5	0	0	2	18.2	3	60	1	9.1
Unemployed	3	6.1	2	18.2	0	0	0	0	0	0	0	0
Retired	32	65.3	4	36.4	8	72.7	0	0	2	40	9	81.8
Disabled	3	6.1	0	0	2	18.2	0	0	0	0	1	9.1
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Age of the sample	65.9	12.3	58.5	16.7	72.2	8.3	66	6.1	56.6	16.2	72.3	5.2
Disease duration	15.6	14.3	17.4	17.1	14.3	9.8	13.5	8.2	9	16.8	22	20.6

Abbreviations: CHF, chronic heart failure; COPD, chronic obstructive pulmonary disease, SD, standard deviation; DM2, diabetes mellitus type 2; PD, Parkinson's disease; RA, rheumatoid arthritis.

data was < 5% (Smith et al., 2005) and floor and ceiling effect were deemed acceptable if they were < 15% (McHorney & Tarlov, 1995).

Preliminary aspects of the internal consistency were tested by Cronbach's alpha coefficient (criterion value > 0.60) (Aaronson et al., 2002), item-total correlation (corrected for overlap; criterion value, $r_s \geq 0.30$) (Hobart et al., 2004) and item homogeneity (criterion value > 0.20) (Eisen et al., 1979).

The following types of *validity* were evaluated: content, internal and known-groups validity. Content validity was established through a *bespoke* questionnaire related to the LwLTC Scale and the PPI group. Data were qualitative and were analysed by the research team. Internal validity between the LwLTC Scale dimensions was measured using the standard $r_s = 0.30$ – 0.70 (Hobart et al., 2004; van der Linden et al., 2005) and known-groups validity was also evaluated for gender, marital status, educational level, employment status and type of LTC (Fayers & Machin, 2007). Mann-Whitney and Kruskal-Wallis tests were used for group's comparison.

Data analysis was undertaken with the software package SPSS 25.0.

3.2.7 | Ethical considerations

The study was approved by the Ethics Committee of the University of Southampton (ERGO) (reference number 53,537) and by all the voluntary organizations participating in the study. All participants gave their signed consent to participate in a voluntary way in the study after receiving the pertinent written and verbal information. All data, including information on the participants' identity, were handled in full confidentiality throughout the research process.

Is it important to highlight that every change and/or modification carried out in the study methodology, as for example data collection procedure due to the COVID-19, were newly approved by the pertinent ethics committee after sending amendments to meet governance requirements and ensure researchers and participants safety.

4 | RESULTS

A total sample of 49 patients living with RA, PD, DM2, CHF and COPD was included in this pilot study of the LwLTC Scale English version.

TABLE 2 Acceptability of the LwLTC Scale for the total sample

	Missing data	Mean	Median	Standard deviation	Observed range	Floor effect (%)	Ceiling effect (%)
Domain 1—Acceptance	0	9.4	10	4.1	0–16	2	2
Item_1	0	2.3	2	1.2	0–4	10.2	14.3
Item_2	0	3.1	4	1.3	0–4	6.1	57.1
Item_3	0	2.2	2	1.3	0–4	10.2	18.4
Item_4	0	1.8	2	1.2	0–4	22.4	6.1
Domain 2—Coping	0	18.8	18	4.8	6–27	2.0	2.0
Item_5	0	2.7	3	1.2	0–4	6.1	28.6
Item_6	0	3.0	3	1.2	0–4	4.1	44.9
Item_7	0	2.4	3	1.4	0–4	18.4	24.5
Item_8	0	3.4	4	0.9	0–4	2.0	55.1
Item_9	0	2.0	2	1.5	0–4	26.5	20.4
Item_10	0	2.9	3	1.3	0–4	6.1	44.9
Item_11	0	2.3	2	1.2	0–4	6.1	22.4
Domain 3—Self-management	0	11.6	12	2.7	4–16	2.0	2.0
Item_12	0	2.6	3	1.1	0–4	6.1	18.4
Item_13	0	2.9	3	1.0	0–4	2.0	24.5
Item_14	0	3.2	3	0.8	1–4	4.1	40.8
Item_15	0	2.9	3	1.3	0–4	10.2	42.9
Domain 4—Integration	0	15.4	16	3.1	5–20	2.0	4.1
Item_16	0	3.3	3	0.9	0–4	2.0	44.9
Item_17	0	3.2	3	0.9	0–4	2.0	44.9
Item_18	0	3.2	3	1.0	0–4	2.0	49.0
Item_19	0	2.8	3	1.2	0–4	8.2	36.7
Item_20	0	2.9	3	1.1	0–4	6.1	24.5
Domain 5—Adjustment	1	14.2	14	5.3	2–24	2.0	4.1
Item_21	0	3.0	3	1.2	0–5	8.2	40.8
Item_22	0	1.4	1	1.3	0–4	32.7	10.2
Item_23	1	2.3	2	1.1	0–4	8.3	14.6
Item_24	0	3.3	4	1.0	0–4	2.0	61.2
Item_25	0	2.1	2	1.3	0–4	16.3	14.3
Item_26	0	2.1	2	1.3	0–4	10.2	20.4

Abbreviation: LwLTC Scale, Living with Long term condition Scale.

As shown in Table 1, from the total sample 59.2% were female, and 71.4% were married, with an average age of 65.9 ($SD = 12.30$). More than the 50% of the sample had primary and secondary level education and 65.3% were retired. The mean duration of the LTC was 15.6 ($SD = 14.3$) years. See Table 1 for further detail of the total sample and specificities for each LTC.

Regarding feasibility and acceptability, there were no missing data, except in item 23 (domain 5—Adjustment). Results for the domains of the LwLTC Scale English version did not show floor or ceiling effects (2.0% and 4.1%, respectively) and all items reached the maximum

score range, except for item 14 (domain 3—Self-management). For further information, see Table 2.

As shown in Table 3, results related to internal consistency of the total sample show that Cronbach's alpha coefficient ranged between 0.50 (domain 3—Self-management) and 0.84 (domain 2—Acceptance). Item homogeneity index values were higher than 0.20 for all domains and item-total corrected correlation values ranged from -0.14 to 0.80 . See Table 3 for further detail of internal consistency for the total sample.

Regarding internal validity of the LwLTC Scale, as shown in Table 4, domains inter-correlated from 0.20 (domain 1—Acceptance

and domain 2—Coping) to 0.59 (domain 4—Integration and domain 5—Adjustment). Finally, according to known-groups validity it was identified that the LwLTC Scale was able to detect statistically significant differences about type of LTCs. No statistically significant differences were found according to gender, marital status, educational level and employment situation. See Table 5 for further detail.

Taking into account the *bespoke* questionnaire about the LwLTC Scale and the PPI, results related to content validity demonstrated that the LwLTC Scale was useful and could unfold relevant aspects of the person. In addition, feedback provided by the participants provided insights that were used to improve the content and clarity of some items. Participants found negative connotations in the word “fight” in item 5 (*I try to cope and fight the disease*). Item 19 (domain 4—Integration), and items 21 and 23 (domain 5—Adjustment) were identified as irrelevant and/or ambiguous to be asked when living with an LTC, as DM2. Furthermore, the item 25 (*despite the problems the LTC creates, I have found new meaning in my life*) was identified as an odd item for people with DM2 and PD.

5 | DISCUSSION

The overarching aim of this pilot study was to produce an English version of the LwLTC Scale and to establish the preliminary psychometric properties. The cross-cultural adaptation of the LwLTC Scale Spanish version to the English version was carried out rigorously according to international standards. Besides, the results emerged in the pilot study indicate that the English version of the LwLTC Scale shows satisfactory preliminary psychometric properties.

Considering the quality of data, results were excellent with 99% of the cases computable and only with one missing data. This was probably due to the support of the researchers during the completion of the scale by the patients. Acceptability for the total sample was also satisfactory, showing that domain items and response options are relevant for the sample included in this study.

Internal consistency was also adequate for the domains of the scale, although domain 3—Self-management was the only one that presented results slightly below the established criteria for the total sample. Various studies (Kang & Ellis-Hill, 2015; Zaragoza et al., 2014) show the suitability of the items contained in the self-management domain and, therefore, this result could be considered acceptable. Item homogeneity was over the minimal standard

threshold for all domains, and the domains 3—Self-management and 4—Integration, did not show adequate coefficient values according to the standards. This means that some of the items grouped in domains 3—Self-management and 4—Integration may be wrongly grouped, measuring perhaps other related concepts. This has not been found in previous pilot or validation studies carried out in other countries, like Spain (Ambrosio, Navarta-Sanchez, Meneses, et al., 2020; Ambrosio, Portillo, et al., 2015; Ambrosio et al., 2016) and were considered surprising because the LwLTC Scale was developed based on important conceptual and empirical work, (Ambrosio, Senosiain, et al., 2015; Portillo et al., 2012; Zaragoza et al., 2014). Nevertheless, this should be interpreted with caution because of the size of the study sample ($n = 49$). Therefore, further analyses will be needed in the main validation of the scale to confirm or discard this.

In relation to the preliminary results related to the validity of the LwLTC Scale, overall, results were satisfactory. Regarding content validity, participants described the LwLTC Scale as a useful tool that helped them to express their daily concerns about the disease. The usefulness and adequacy of the scale have also been highlighted in previous pilot studies carried out in a Spanish-speaking population (Ambrosio, Navarta-Sanchez, Meneses, et al., 2020; Ambrosio, Portillo, et al., 2015). However, due to the cultural differences between countries (Spain and UK) some of the participants in the present study expressed their disagreement with some items regarding the ambiguity of the meaning like the use of the word “fight.” Due to this cultural discrepancy, and following the cross-cultural adaptation of the Spanish version of the LwLTC Scale to the English culture, the verb “fight” was replaced by the verb “face.” This change was made in accordance with the original author of the scale.

Regarding the internal validity, a strong correlation was identified among the five domains of the scale, except in one of the items values regarding domain 1—Acceptance (0.20). This low value is coherent and could be explained by previous conceptual and empirical studies carried out in the living with LTC field (Ambrosio, Navarta-Sanchez, Meneses, et al., 2020; Ambrosio, Portillo, et al., 2015; Ambrosio, Senosiain, et al., 2015; Portillo et al., 2012; Zaragoza et al., 2014) where Acceptance is considered an internal, illness-independent process through which the person with LTCs recognizes and assumes that presents an LTC. Moreover, accepting the disease is always the starting point for living successfully with an LTC (Ambrosio, Senosiain, et al., 2015). Thereby, for this pilot study we

TABLE 3 Internal consistency of the LwLTC Scale for the total sample

	Number of items	Cronbach's alpha	Item-total corrected correlation (range)	Homogeneity index
Domain 1—Acceptance	4	0.84	0.61–0.80	0.58
Domain 2—Coping	7	0.62	0.48–0.26	0.21
Domain 3—Self-management	4	0.50	0.24–0.42	0.21
Domain 4—Integration	5	0.56	–0.14–0.70	0.23
Domain 5—Adjustment	6	0.81	0.38–0.74	0.40

Abbreviation: LwLTC Scale: Living with Long term condition Scale.

TABLE 4 Internal validity of the LwLTC Scale for the total sample

	Domain 1—Acceptance	Domain 2—Coping	Domain 3—Self-management	Domain 4—Integration
Domain 2—Coping	0.20			
Domain 3—Self-management	0.32	0.38		
Domain 4—Integration	0.39	0.38	0.34	
Domain 5—Adjustment	0.40	0.51	0.36	0.59

Abbreviation: LwLTC Scale: Living with Long term condition Scale.

TABLE 5 Known-groups validity

Variable	Categories	LwLTC Scale	p value
Gender	Men	74.0 ± 3.3	0.07
	Women	66.1 ± 2.6	
Marital status	Single	69.4 ± 3.3	0.32
	Married	69.1 ± 2.6	
	Widower	80.7 ± 1.2	
	Other	64.2 ± 7.7	
Educational level	Basic—primary studies	68.7 ± 3.4	0.97
	Secondary studies	68.0 ± 4.4	
	University—postgraduate studies	71.8 ± 6.6	
Employment situation	Employed	69.5 ± 6.8	<0.95
	Unemployed	70.0 ± 16.1	
	Retired	68.7 ± 15.8	
	Disabled	76.0 ± 18.0	
Long-term condition	Rheumatoid arthritis	74.4 ± 6.8	<0.002 [*]
	Parkinson's disease	62.6 ± 14.3	
	Diabetes mellitus type 2	76.8 ± 14.6	
	Chronic heart failure	47.0 ± 13.9	
	Chronic obstructive pulmonary disease	74.1 ± 8.3	

Note: Mean ± standard deviation. Mann-Whitney test for gender, Kruskal-Wallis test with Bonferroni correction for the rest of variables.

**p* < .05 statistically significant.

included people living with LTCs with different diagnosis durations to cover people in different stages of the daily living. Nevertheless, as these are just preliminary findings related to the domains of the LwLTC Scale, further psychometric analyses are needed to verify them in a larger and more representative sample size during the main validation study that will follow.

Finally, results related to known-groups validity were really clarifying and indicated that the English version of the LwLTC Scale evaluates equally the degree of living with a long-term illness in all individuals independently of gender, marital status, educational level and employment situation. This result could mean that LwLTC Scale could be used with a diverse sample of people with LTCs without discriminating their gender, educational level or employment situation. This characteristic of the LwLTC Scale becomes really important in nowadays when there is a higher prevalence of people living with LTCs in deprived/disadvantaged communities (Department of Health, 2012). In this sense, the English version of the LwLTC Scale

could be specially useful and acceptable for people with lower socio-economical and cultural resources and thus with an enhanced referral process decrease health inequalities and access to services and resources.

Additionally, statistical differences were identified when applying the LwLTC Scale to participants with different LTCs. This finding gains special relevance when testing a generic measuring scale, like the LwLTC Scale because the scale could capture differences across LTCs and this would allow health and social care professionals, such as nurses to implement person-centred care pathways and referral processes, taking into account the specificities of each LTC. To our knowledge, this is the only generic patient-reported outcome measure that could identify differences depending on the disease. Other existing generic scales as the Long-Term Conditions Questionnaire (Potter et al., 2017) evaluated the concept "living well" with LTCs in a generic way without also capturing LTCs particularities.

Taking into account emerged results in this pilot study, the English version of the LwLTC Scale is a potential clinical measure to be used by nurse professionals. Apart from apparently presenting satisfactory psychometric results as it was identified in this study, the LwLTC Scale is a short, easy and comprehensive measure to use in everyday practice. Through this scale, nurses could quickly identify how the person is living with one or more than one LTC and consequently prevent further complications and unnecessary use of resources and services. In particular, nurses could provide the patients with specific and individualized choices, such as coping skills and/or adjustment strategies in order to achieve a positive living with the LTC (Ambrosio, Senosiain, et al., 2015). Consequently, patients will become more autonomous and will know how to face with the LTC and deal with complications it and reducing nurses' workload.

6 | LIMITATIONS

This study presents some limitations that have been into account for the main validation study of the LwLTC Scale. First of all, even though all instruments included in this study were self-reported measures the presence of a researcher during the data collection could have influenced the participants' response. However, measures were taken so that researcher was only available to explain the study and ensure that all instruments were completed and solved any questions about the project procedures. Besides, none of the participants expressed feeling uncomfortable or influenced by the researcher. Secondly, the small sample size of this study limits the real value of the psychometric properties of this new English version of the LwLTC Scale, such as Cronbach's alpha or internal validity. Nevertheless, this is acceptable considering the purpose of the preliminary study prior to the formal validation study, which is to complete the cross-cultural adaptation of the scale and produce the final version (tested) for the validation study. Finally, we cannot ignore the impact of COVID-19 to research worldwide and this project was not an exception. Social distancing measures caused difficulties in the recruitment process and required the introduction of a new methodology for data collection, which, despite keeping the project running, could have added spurious variability to the results.

This study also presents several strengths such as the prototypical and diversity of LTCs selected, the reach of participants through a community approach instead of just through the healthcare system, and a strong PPI strategy and input. Besides, the general approach of this study was to develop one language version of the LwLTC Scale that could be used in all countries in which English is spoken. The benefit of this approach is that the final translations should not require further adaptation for other countries although testing with patients in new countries would be recommended. Finally, even the recruitment process during the lockdown of COVID-19 was a challenge, through this pilot study we had the opportunity to identify the versatility in the use of the LwLTC Scale, which could be applied face to face or remotely through telephone interview.

7 | CONCLUSIONS

The preliminary psychometric properties of the English version of the LwLTC Scale are satisfactory and promising. However, these results do not automatically guarantee the success of the LwLTC Scale in clinical practice and research in the UK. This pilot study is just a first approximation of the scale in a small sample size of English-speaking people living with LTCs in the UK. Therefore, cautious interpretation is needed and high expectations are in place for the main validation study, which is now in process.

ACKNOWLEDGEMENTS

The authors would like to thank the NIHR Applied Research Collaboration Wessex for the financial support in the development of this project. Besides, the authors really appreciate FACIT services for the transcultural adaptation of the scale. The authors also would like to acknowledge the collaboration of people with long-term conditions in the project.

CONFLICT OF INTEREST

The authors declare having no conflict of interests.

AUTHORS' CONTRIBUTIONS

Ambrosio L is principal author of the original scale in Spanish, interpreted the results, drafted the whole article and approved the final version for publication. Hislop-Lennie K contributed to project conception, data collection, critical revision and substantial contribution of the article, and approval of the final version for publication. Barker H collected the data, critically reviewed and substantially contributed to the article, and approved the final version for publication. Culliford D made statistical data analysis, critical revision and substantial contribution of the article, and approval of the final version for publication. Portillo MC is principal investigator of the project and responsible for the funding of the project, supervision and finalization of the cross-cultural adaptation of the Scale to English, conception and design of the work, oversight of the project, interpretation of the findings, drafting the article, critical revision and substantial contribution of the article, and approval of the final version for publication. The corresponding author, in representation of the rest of the undersigning individuals, guarantees the precision, transparency and honesty of the data and information contained in the study; additionally that none of the relevant information has been omitted and that all discrepancies among the authors have been adequately solved and described.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ORCID

Leire Ambrosio  <https://orcid.org/0000-0002-9450-7210>

Mari Carmen Portillo  <https://orcid.org/0000-0003-1583-6612>

REFERENCES

- Aaronson, N., Alonso, J., Burnam, A., Lohr, K. N., Patrick, D. L., Perrin, E., & Stein, R. E. (2002). Assessing health status and quality-of-life instruments: Attributes and review criteria. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation*, 11(3), 193–205. <https://doi.org/10.1023/a:1015291021312>
- Ambrosio, L., Navarta-Sanchez, M. V., Carvajal, A., & Garcia-Vivar, C. (2020). Living with chronic illness from the family perspective: an integrative review. *Clinical Nursing Research*, 1–12. <https://doi.org/10.1177/1054773820947983>
- Ambrosio, L., Navarta-Sanchez, M., Meneses, A., & Rodriguez-Blazquez, C. (2020). Escala de convivencia con un proceso crónico: Estudio piloto en pacientes con enfermedades crónicas. *Atención Primaria*, 52(3), 142–150. <https://doi.org/10.1016/j.aprim.2018.08.008>
- Ambrosio, L., & Portillo, M. C. (2018). Tools to assess living with a chronic illness: A systematic review. *Enfermería Clínica*, 28(4), 220–229. <https://doi.org/10.1016/j.enfcli.2018.04.003>
- Ambrosio, L., Portillo, M. C., Rodriguez-Blazquez, C., Carvajal, A., & Martinez-Martin, P. (2015). A pilot study on the living with a chronic process scale in patients with Parkinson's disease. *Revista De Neurología*, 61(10), 447–453. <https://doi.org/10.33588/rn.6110.2015158>
- Ambrosio, L., Portillo, M. C., Rodríguez-Blázquez, C., Rodríguez-Violante, M., Castrillo, J. C. M., Arillo, V. C., Garretto, N. S., Arakaki, T., Dueñas, M. S., Álvarez, M., Ibáñez, I. P., Carvajal, A., & Martínez-Martín, P. (2016). Living with chronic illness scale: international validation of a new self-report measure in parkinson's disease. *NPJ Parkinson's Disease*, 2, 16022. <https://doi.org/10.1038/npjparkd.2016.22>
- Ambrosio, L., Portillo, M. C., Rodriguez-Blazquez, C., Rojo, J. M., Martinez-Martin, P., Violante, M. R., Castrillo, J. C. M., Arillo, V. C., Garretto, N. S., Arakaki, T., Dueñas, M. S., & Alvarez, M. (2019). Influencing factors when living with Parkinson's disease: A cross-sectional study. *Journal of Clinical Nursing*, 28(17–18), 3168–3176. <https://doi.org/10.1111/jocn.14868>
- Ambrosio, L., Senosiain, J., Riverol, M., Anaut, S., de Cerio, D., Ayesa, S., Ursúa, M. E., & Portillo, M. C. (2015). Living with chronic illness in adults: A concept analysis. *Journal of Clinical Nursing*, 24(17–18), 2357–2367. <https://doi.org/10.1111/jocn.12827>
- Bowling, A. (2014). *Research Methods In Health: Investigating Health And Health Services*, 4th ed. University Press.
- Department of Health. (2012). Report: long term conditions compendium of information (3rd ed). https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216528/dh_134486.pdf
- DeVellis, R. F. (2012). *Scale Development. Theory and Applications*. SAGE Publications.
- Eisen, M., Ware, J. E., Donald, C. A., & Brook, R. H. (1979). Measuring components of children's health status. *Medical Care*, 17(9), 902–921. <https://doi.org/10.1097/00005650-197909000-00003>
- Fayers, P., & Machin, D. (2007). *Quality of Life: The assessment, analysis and interpretation of patient-reported outcomes*, 2nd ed. John Wiley & Sons.
- Haahr, A., Kirkevold, M., Hall, E., & Ostergaard, K. (2010). Living with advanced Parkinson's disease: A constant struggle with unpredictability. *Journal of Advanced Nursing*, 67(2), 408–417. <https://doi.org/10.1111/j.1365-2648.2010.05459.x>
- Hobart, J. C., Razi, A., Lamping, D. L., Fitzpatrick, R., & Thompson, A. J. (2004). Improving the evaluation of therapeutic interventions in multiple sclerosis: Development of a patient-based measure of outcome. *Health Technology Assessment (Winchester, England)*, 8(9), 1–48. <https://doi.org/10.3310/hta8090>
- International Test Commission (2010). *International test commission guidelines for translating and adapting tests*. Available from: <http://www.intestcom.org>
- Kang, M. Y., & Ellis-Hill, C. (2015). How do people live life successfully with Parkinson's disease? *Journal of Clinical Nursing*, 24, 2314–2322. <https://doi.org/10.1111/jocn.12819>
- Lim, S. Y., Tan, A. H., Fox, S. H., Evans, A. H., & Chai Low, S. (2017). Integrating Patient Concerns into Parkinson's Disease Management. *Current Neurology and Neuroscience Reports*, 17, 3. <https://doi.org/10.1007/s11910-017-0717-2>
- Martinez-Martin, P., & Frades Payo, B. (2006). Desarrollo de un instrumento de valoración de calidad de vida relacionada con la salud. In P. Martínez-Martín (Ed.), *Calidad de vida en neurología* (pp. 33–48). Ars Medica.
- Martinez-Martin, P., Rodriguez-Blazquez, C., Forjaz, M. J., & Chaudhuri, K. R. (2014). *Guide to Assessment Scales in Parkinson's Disease*. Springer Healthcare.
- May, C. R., Cummings, A., Myall, M., Harvey, J., Pope, C., Griffiths, P., Roderick, P., Arber, M., Boehmer, K., Mair, F. S., & Richardson, A. (2016). Experiences of long-term life-limiting conditions among patients and carers: What can we learn from a meta-review of systematic reviews of qualitative studies of chronic heart failure, chronic obstructive pulmonary disease and chronic kidney disease? *British Medical Journal Open*, 6(10), 1–15. <https://doi.org/10.1136/bmjopen-2016-011694>
- McHorney, C. A., & Tarlov, A. R. (1995). Individual-patient monitoring in clinical practice: Are available health status surveys adequate? *Quality of Life Research*, 4, 293–307. <https://doi.org/10.1007/BF01593882>
- Mendes, A. (2015). Ten years on from the National Service Framework for long-term conditions: How far have we come? *British Journal of Community Nursing*, 20(3), 150–151. <https://doi.org/10.12968/bjcn.2015.20.3.150>
- Navarta-Sánchez, M. V., Caparrós, N., Fernández, M., De Cerio, D., Ayesa, S., Ursúa Sesma, M. E., & Portillo, M. C. (2017). Core elements to understand and improve coping with Parkinson's disease in patients and family carers: A focus group study. *Journal of Advanced Nursing*, 73, 2609–2621. <https://doi.org/10.1111/jan.13335>
- Navarta-Sanchez, M. V., Senosiain, J. M., Riverol, M., Ursua, M. E., Diaz de Cerio, S., Anaut, S., Caparros, N., & Portillo, M. C. (2016). Factors influencing psychosocial adjustment and quality of life in Parkinson patients and informal caregivers. *Quality of Life Research*, 25(8), 1959–1968. <https://doi.org/10.1007/s11136-015-1220-3>
- NHS (2019). *The NHS long term plan*. Available at: <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf>
- Peduzzi, P., Concato, J., Kemper, E., Holford, T. R., & Feinstein, A. R. (1996). A simulation study of the number of events per variable in logistic regression analysis. *Journal of Clinical Epidemiology*, 49, 1373–1379. [https://doi.org/10.1016/S0895-4356\(96\)00236-3](https://doi.org/10.1016/S0895-4356(96)00236-3)
- Pemberton, S. (2014). Long-Term Conditions - Condition Management or Managing to Live? *British Journal of Occupational Therapy*, 77(5), 221. <https://doi.org/10.4276/030802214X13990455043322>
- Portillo Vega, M. C., Senosiain García, J. M., Arantzamendi Solabarrieta, M., Zaragoza Salcedo, A., Navarta Sánchez, M. V., de Cerio Ayesa, S. D., Riverol Fernández, M., Martínez Vila, E., Luquin Piudo, M. R., Ursúa Sesma, M. E., Corchón Arreche, S., & Moreno Lorente, V. (2012). Proyecto ReNACE. Convivencia de pacientes y familiares con la enfermedad de Parkinson: Resultados preliminares de la Fase I. *Enfermería Neurológica*, 36(1), 31–38. [https://doi.org/10.1016/S2013-5246\(12\)70019-3](https://doi.org/10.1016/S2013-5246(12)70019-3)
- Potter, C. M., Batchelder, L., A'Court, C., Geneen, L., Kelly, L., Fox, D., Baker, M., Bostock, J., Coulter, A., Fitzpatrick, R., Forder, J. E., Gibbons, E., Jenkinson, C., Jones, K., & Peters, M. (2017). Long-term Conditions Questionnaire (LTCQ): Initial validation survey among primary care patients and social care recipients in England. *British Medical Journal Open*, 7(24), 1–12. <https://doi.org/10.1136/bmjopen-2017-019235>

- Prizer, L. P., & Browner, N. (2012). The Integrative Care of Parkinson's Disease: A systematic Review. *Journal of Parkinsonism Disorders*, 2, 79–86. <https://doi.org/10.3233/JPD-2012-12075>
- Public Health Agency of Canada. (2009). *Survey on Living with Chronic Diseases in Canada*. Available from: <http://www23.statcan.gc.ca/imdb-bmdi/pub/document/5160D5T1V1-eng.htm>
- Rector, T. S., Kubo, S. H., & Cohn, I. N. (1987). Patients' self-assessment of their congestive heart failure. Part 2: Content, reliability and validity of a new measure, the Minnesota Living with Heart Failure questionnaire. *Heart Failure*, 3, 198–209.
- Smith, S., Lamping, D., Banerjee, S., Harwood, R., Foley, B., Smith, P., Cook, J., Murray, J., Prince, M., Levin, E., Mann, A., & Knapp, M. (2005). Measurement of health-related quality of life for people with dementia: Development of a new instrument (DEMQOL) and an evaluation of current methodology. *Health Technology Assessment*, 9(10), 1–93. <https://doi.org/10.3310/hta9100>
- Soundy, A., Stubbs, B., & Roskell, C. (2014). The experience of Parkinson's disease: A systematic review and meta-ethnography. *The Scientific World Journal*, 2014, 1–19. <https://doi.org/10.1155/2014/613592>
- Sousa, V. D., & Rojjanasirirat, W. (2011). Translation, adaptation and validation of instruments or scales for use in cross-cultural health care research: A clear and user-friendly guideline. *Journal of Evaluation in Clinical Practice*, 17, 268–274. <https://doi.org/10.1111/j.1365-2753.2010.01434.x>
- van der Linden, F. A. H., Kragt, J. J., Klein, M., van der Ploeg, H. M., Polman, C. H., & Uitdehaag, B. M. J. (2005). Psychometric evaluation of the multiple sclerosis impact scale (MSIS-29) for proxy use. *Journal of Neurology, Neurosurgery and Psychiatry*, 76(12), 1677–1681. <https://doi.org/10.1136/jnnp.2005.065227>
- Wild, D., Eremenco, S., Mear, I., Martin, M., Houchin, C., Gawlicki, M., Hareendran, A., Wiklund, I., Chong, L. Y., von Maltzahn, R., Cohen, L., & Molsen, E. (2009). Multinational trials—recommendations on the translations required, approaches to using the same language in different countries, and the approaches to support pooling the data: The ISPOR Patient-reported outcomes translation and linguistic validation good research practices task force report. *Value in Health*, 12, 430–440. <https://doi.org/10.1111/j.1524-4733.2008.00471.x>
- World Health Organization (WHO) (2020). *Noncommunicable Diseases*. Available from: <https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases>
- Zaragoza, A., Senosiain, J. M., Riverol, M., Anaut, S., Diaz de Cerio, S., Ursua Sesma, M. E., & Portillo, M. C. (2014). Elementos clave en el proceso de convivencia con la enfermedad de Parkinson de pacientes y familiares cuidadores. *Anales Del Sistema Sanitario Navarra*, 37(1), 69–80. <https://doi.org/10.4321/S1137-66272014000100008>

How to cite this article: Ambrosio L, Hislop-Lennie K, Barker H, Culliford D, Portillo MC. Living with Long term condition Scale: A pilot validation study of a new person centred tool in the UK. *Nurs Open*. 2021;8:1909–1919. <https://doi.org/10.1002/nop2.859>