Eight lessons from 2 years of use of the Post-COVID-19 Functional Status scale

To the Editor:

The number of confirmed cases of coronavirus disease 2019 (COVID-19) worldwide exceeded 750 million as of February 2023 [1], leaving an estimated 65 million individuals experiencing post-acute sequelae of COVID-19 or "long COVID", or a modelled estimate of 6.2% of individuals experiencing long COVID symptoms 3 months after symptomatic SARS-CoV-2 infection [2, 3]. Early in the pandemic, we proposed the Post-COVID-19 Functional Status (PCFS) scale in the *European Respiratory Journal* [4], which resulted from a slight adaptation of the Post-Venous thromboembolism Functional Status (PVFS) scale developed in 2019 [5, 6]. The PCFS scale is designed to monitor functional recovery and identify patients with incomplete or poor recovery after COVID-19 in research and clinical practice.

Since the introduction of the PCFS scale, its uptake and incorporation in the COVID-19 research community has been notable, with the original study gaining an Altmetrics score of 149 and being cited more than 270 times, and the scale being recommended in guidelines, including the World Health Organization's guideline on clinical management of COVID-19 [7–12]. To investigate the application of the PCFS scale in detail, we evaluated the available literature and distributed a survey to users of the scale. The PCFS scale and manual for the structured interview and patient-reported assessment, details of the literature searches and survey, and a full report on the findings can be found on our PCFS resource page [13, 14]. In this research letter, we summarise the main findings.

We learned that the PCFS scale has been adopted in numerous countries and settings. More than 25 translations are available. In addition to formal cross-cultural adaptation studies, several validation studies have been performed as part of translation processes that have varying quality due to limited resources and the pressing circumstances during the COVID-19 pandemic.

We have also learned that the face validity, construct validity and concurrent validity of the PCFS scale are adequate, while some psychometric properties, such as predictive validity, remain to be studied. Several studies evaluated the validity of the PCFS scale, showing that the scale appears to measure what it purports to measure, and correlates reasonably with other relevant outcome measures. Moreover, the inter-rater agreement of the structured interview was shown to be substantial, both at baseline and after 6-month follow-up of COVID-19 survivors [15].

Based on the literature and users' experiences, we have learned that the use of the PCFS scale as an additional outcome measure is supported. For now, the scale is intended to be used in addition to other (patient-reported) instruments to evaluate the consequences of COVID-19 on functional status; not as a stand-alone instrument replacing other relevant outcome measures.

We have learned that the scale is considered to be useful. The survey was distributed to 100 users, of whom 54 completed the survey. The 54 participants rated their experience with use of the PCFS scale from 0 (disagree) to 10 (agree): a median of 8 was scored for "easy for physicians to use and understand" and "recommend the scale to other colleagues", and median 10 for "easy for patients to use and understand" and "useful as a tool in the SARS-CoV-2 pandemic". In articles in which the authors stated an opinion on

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Based on the literature and users' experiences, lessons could be learned after 2 years' use of the Post-COVID-19 Functional Status (PCFS) scale, that could contribute to its optimal use. All in all, the PCFS scale provided added value during the pandemic. https://bit.ly/3KkI5Ak

the PCFS scale, its use was recommended or the scale was considered useful. None of the articles described the scale as unusable or discouraged its use.

We have learned that reporting the full methodology when using the PCFS scale is crucial for optimal interpretation. Of the articles, study protocols and trial registrations in which the scale was used as an outcome measure (n=103), 64% did not specify how the scale was assessed. Describing the assessment method(s) (*i.e.* structured interview, questionnaire or flowchart), timing of assessment(s), and analysis methods ensures transparency and reproducibility. The majority of survey participants considered all three assessment methods "important" or "extremely important", with the questionnaire being the most favourable assessment method. Notably, 41% of the participants used the scale in a clinical setting or for both clinical and scientific work. Since studies evaluating the psychometric properties used several assessment methods, we cannot provide a single recommendation on how to best assess the PCFS in clinical practice, but we do recommend to not mix methods for one assessment. Assessment through the structured interview helps reducing subjectivity and allows for blinding, and is therefore recommended in research settings.

As standardisation of measurement will allow for comparisons, the PCFS scale is intended to be assessed at specified time points (as described in the manual: 1) at discharge; 2) in the first weeks after discharge, *e.g.* 4 and 8 weeks post-discharge; and 3) after 6 months). Of these, a 3-month follow-up period was most commonly used to monitor recovery after COVID-19. Results of the survey underline this, as part of the participants applied the scale at 12 weeks after discharge. Assessment of the PCFS over time enables to evaluate the course of symptoms and functional status, and to identify patients with functional deterioration or insufficient recovery. Notably, only in about half of the 150 identified published articles, study protocols and trial registrations, the time window around assessment of the PCFS was reported. More importantly, a time window of several weeks was found in a considerable number of studies. Based on this, we stress that standardised measurement and applying a time window of one assessment that is as tight as possible will optimise the use of the PCFS scale. To evaluate functional status over time, assessment of a pre-COVID-19 scale grade could be considered, in particular in patients who have pre-existing functional disabilities, but more research is needed to recommend this practice.

Furthermore, we have learned that the inclusion of scale grade 5 ("death") is not always taken into account. Grade 5 is part of the scale to allow all included patients to be assessed and not only focus on survivors, thus preventing selection bias. Remarkably, according to the 14 studies that reported the distribution of PCFS scale grades, grade 5 was almost absent which could be the result of incomplete assessment or reporting. Based on the survey in which participants were asked about the scale grade distribution they had encountered (roughly), grade 5 ("death") was reported at some time points, supporting the idea that a survivor bias is present in some PCFS studies.

Being an ordinal scale rather than a score or binary measure, the scale can be used to classify patients into categories leading to unequivocal interpretation, and at the same time, enables to assess patients within a broad range of functional limitations. Of the 72 published articles in which analyses were performed, regression analysis was performed in nine studies: only two used ordinal logistic regression, while seven dichotomised the PCFS and used binary logistic regression, thus reducing the score's usefulness. Considering this, we strongly suggest to consciously consider the ordinality of the PCFS scale during statistical analysis.

TABLE 1 The eight lessons that could be learned after the 2-year use of the Post-COVID-19 Functional Status (PCFS) scale
1 The PCFS scale is adopted in numerous countries and settings
2 Face validity, construct validity and concurrent validity are adequate, while some psychometric properties, such as predictive validity, remain to be studied
3 Use of the PCFS scale as additional outcome measure – in addition to other relevant measures – is supported by the community
4 The scale is considered to be useful, based on the literature and a survey among users
5 Reporting the full methodology when using the PCFS scale is crucial for optimal interpretation
6 Standardised measurement and applying a tight time window around one assessment will optimise its interpretability
7 Inclusion of scale grade 5 ("death") is not always taken into account, which could lead to bias
8 The ordinality of the PCFS scale should be considered during statistical analysis in order to use the PCFS scale to its full potential

Based on the available literature and experiences of users, we have summarised the eight lessons that could be learned after the 2-year use of the PCFS scale (table 1). We acknowledge that many studies that evaluated the psychometric properties or used the scale as an outcome measure were performed under the pressing circumstances of the pandemic. To optimise the use of the scale, the lessons from its 2-year use should be taken into account. Even so and ultimately, the PCFS scale has been shown to provide added value during the COVID-19 pandemic.

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