

Is there psychometric evidence to support the use of the EQ-5D in long COVID?

A systematic review

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Background

Long COVID – COVID-19 symptoms or sequelae that persist for longer than three months – is a significant public health problem. It is estimated that 6% of individuals who get COVID-19 will go on to develop long COVID.[1] Vaccination appears to have reduced the risk; however millions still suffer symptoms.

Long COVID is not a single condition, but an umbrella term for a myriad of symptoms including brain fog, fatigue, breathlessness, cardiovascular problems, pain, and mental health problems. More than 200 symptoms have been identified that impact multiple organ systems.

Long COVID was first acknowledged as a condition in mid 2020. At that point studies began to assess the clinical manifestation of long COVID, as well as the impact long COVID has on the health-related quality of life (HRQoL). The myriad of symptoms raises issues about the most appropriate HRQoL instrument. While a number of condition-specific measures have been developed (e.g. C19-YRS, PAC-19QoL), generic HRQoL measures are also of value, as comparisons can be made across populations and conditions. However, this is only true if the HRQoL measures have been validated.

As a new condition, long COVID offers an opportunity to understand how (and indeed whether) instrument choice is justified and assessed.

Objective

The EQ-5D is one of the most widely used measures of HRQoL. It has been validated in many chronic conditions, therefore it is important to understand the extent to which the EQ-5D has been validated in long COVID, and in the face of limited validation evidence how the use of EQ-5D is justified.

Methods

A systematic review was undertaken to identify articles published between 2020 and August 2024 that used the EQ-5D to measure HRQoL in individuals with long COVID. The systematic review was conducted in accordance with the PRISMA 2020 Checklist and is registered with PROSPERO.[2]

Articles were identified, screened and then included for data extraction (see Figure 1). All variations of EQ-5D were included as search terms, as well as all terms for long COVID. Three authors undertook the reviews, to reduce bias and provide quality checks.

Full-text articles that didn't address one of the following about the EQ-5D were excluded: validity, reliability, responsiveness, strength, weakness, why they did or didn't use it, why they used it as a gold standard comparison, or had only an abstract available.

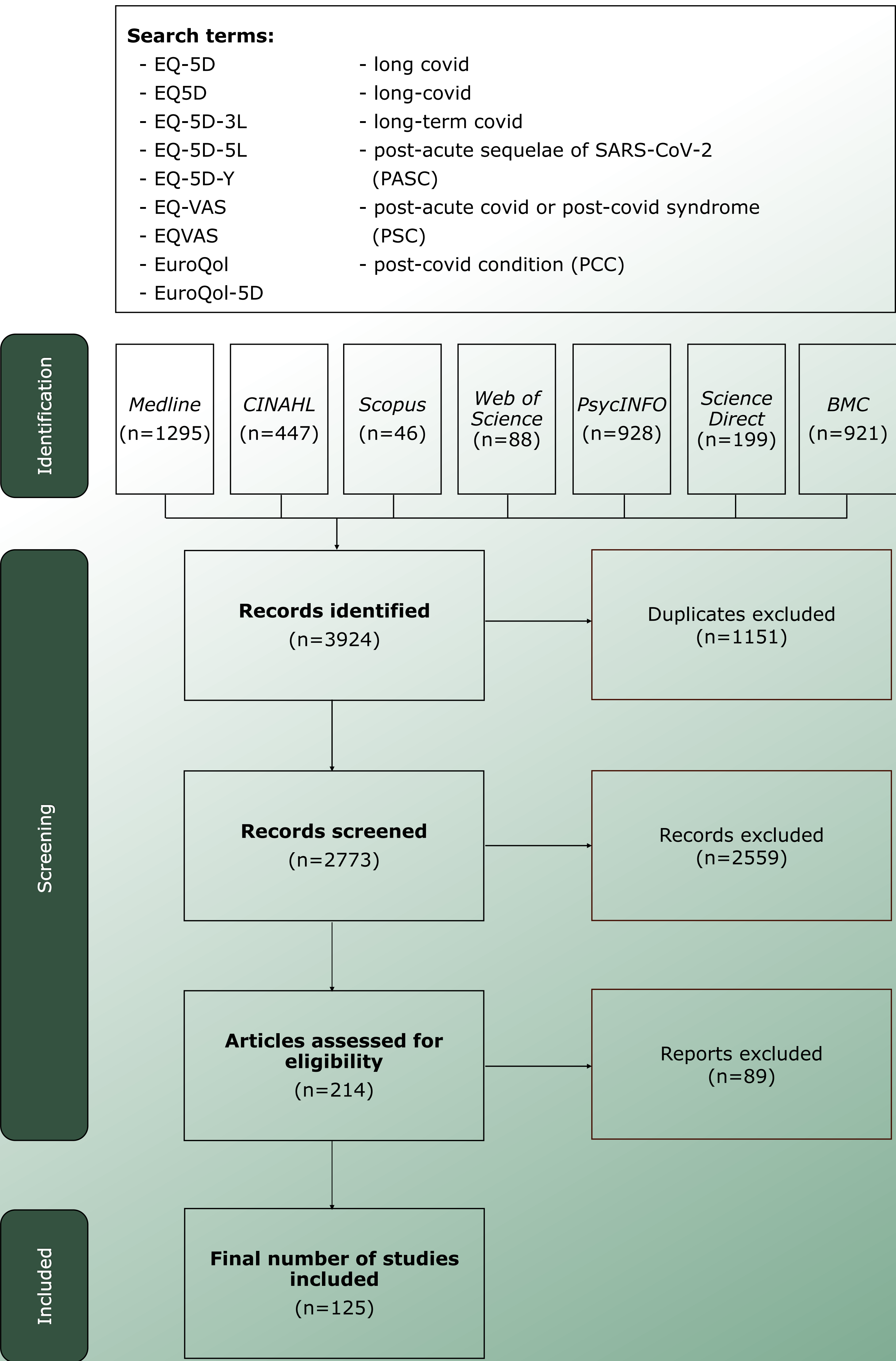
The information extracted informed thematic analyses of the evidence generated or referenced by the paper for using the EQ-5D for long COVID, particularly regarding its psychometric properties.

References

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Figure 1: PRISMA Flow Diagram



Results

A total of 214 papers were identified. All abstracts were screened and then the full texts were reviewed for eligibility, with 125 articles included in the analysis.

The vast majority of papers that report findings on the impact of long COVID on HRQoL using the EQ-5D do not include a reference to support the inclusion of the instrument. They refer to a 'validated instrument' or a 'generic instrument'. Those studies that stated the EQ-5D was a valid measure tended to reference seminal EQ-5D articles (e.g. [3]), but these in themselves do not provide evidence of validity. Some studies provided reference to the EQ-5D as a valid measure of population health, or that validity had been established in other conditions, so at least appear to have considered the applicability of the instrument.

There is one instance of validation of the EQ-5D in long COVID.[4] Spanish researchers explored the internal consistency, test-retest reliability, and construct validity of the EQ-5D-5L in people with long-COVID; they found the EQ-5D-5L to have good psychometric properties.

Another paper has considered whether the EQ-5D-5L is sensitive to the most common symptoms of long COVID;[5] while elsewhere the EQ-5D has been used as a gold standard instrument in the development of a COVID-specific HRQoL measures (e.g. [6]), despite providing no evidence of the EQ-5D's psychometric properties in this population.

Conclusion

Although long COVID has only been a recognised condition since 2020, the popularity of the EQ-5D as a measure of HRQoL has been well established in the literature. What is missing however is evidence of the psychometric properties of the instrument in long COVID.

Despite this lack of evidence the PC-COS project – which used a Delphi process to develop a core outcome set for post-COVID-19 condition – has recommended the EQ-5D-5L as a generic measure.[7] Similarly, EQ-5D-5L appears in Canadian post-COVID guidelines.

This raises a question: does use alone provide enough evidence of validation?

Arguably, the early research on the HRQoL of long COVID in 2020/2021 was justified in providing limited supporting evidence with respect to the EQ-5D. However, if the instrument is to be used in health technology assessments (should effective pharmacological agents be identified) to estimate QALYs, will there be enough evidence to support their use? It would be disappointing if adoption decisions were impacted due to a lack of validation evidence. For this reason, researchers are encouraged to further explore the psychometric properties of the EQ-5D, establishing its validity, reliability, responsiveness, strengths and weaknesses in order to support wider adoption of the instrument in disease and cohort studies.



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