

Manual for the Use of Hypertrophic Cardiomyopathy Symptoms Questionnaire (HCMSQ) V2.0 7d-recall Version Scoring Guide

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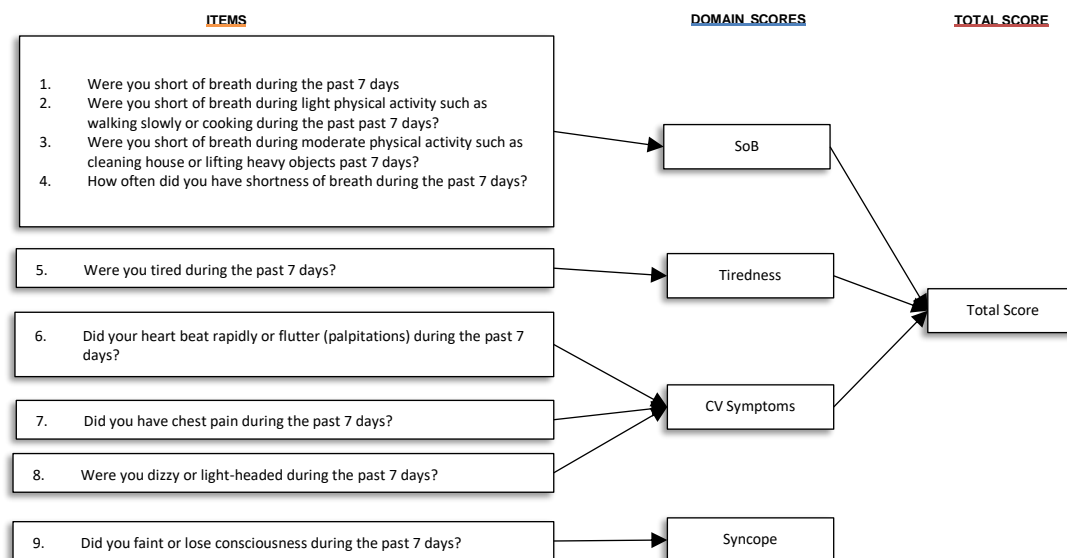
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Introduction

The HCMSQv2.0 7d-recall version contains nine patient-reported symptom items that patients with hypertrophic cardiomyopathy answer to report their symptom status during the past 7 days. These nine HCMSQv2.0 7d-recall items form four domains: shortness of breath (SoB), tiredness, cardiovascular (CV) symptoms, and syncope. Of these four HCMSQ domains, two are multi-item (SoB and CV symptoms), while HCMSQ tiredness and syncope are single item domains. Domain scores are computed for three domains: SoB, tiredness and CV symptoms domains as described below. These three domain scores (SoB, tiredness and CV symptoms) are used to create the HCMSQ total score. For all domain and the total symptoms scores, lower scores indicate better health whereas a higher score indicates a greater symptom burden.

The HCMSQ v2.0-24h Recall instrument is a validated version used in the EXPLORER-HCM clinical trial¹ and has a recall period of the past 24 hours. The HCMSQ v2.0 7-d Recall instrument in contrast was created to facilitate real-world clinic use outside of a trial and has a recall period of the past 7 days. Efforts to validate the 7-day Recall version are still ongoing.

Figure 1: Conceptual Framework of the HCMSQv2.0



¹ References:

Reaney M, Allen V, Sehnert AJ, et al. Development of the Hypertrophic Cardiomyopathy Symptom Questionnaire (HCMSQ): A New Patient-Reported Outcome (PRO) Instrument. *PharmacoEconomics - Open*. 2022.

Reaney M, Addepalli P, Allen V, et al. Longitudinal Psychometric Analysis of the Hypertrophic Cardiomyopathy Symptom Questionnaire (HCMSQ) Using Outcomes from the Phase III EXPLORER-HCM Trial. *Pharmacoecon Open*. 2022.

Scoring Guide

HCMSQv2.0-7d Recall SoB Domain Score:

- Code responses to each of **Items 1-4** as follows:

Core Symptom	Item	Question	Response Options
Shortness of Breath	1	Were you short of breath during the past 7 days?	0 = Not at all 1 = Mildly 2 = Moderately 3 = Severely 4 = Very Severely
	2	Were you short of breath during light physical activity such as walking slowly or cooking during the past 7 days?	. = I had no opportunity to do light physical activity 0 = Not at all 1 = Mildly 2 = Moderately 3 = Severely 4 = Very Severely 5 = Too short of breath to do the activity
	3	Were you short of breath during moderate physical activity such as cleaning house or lifting heavy objects during the past 7 days?	. = I had no opportunity to do moderate physical activity 0 = Not at all 1 = Mildly 2 = Moderately 3 = Severely 4 = Very Severely 5 = Too short of breath to do the activity
	4	How often did you have shortness of breath during past 7 days?	0 = Never 1 = Seldom 2 = Sometimes

			3 = Often 4 = Almost Always
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- If the ‘I had no opportunity to do light physical activity’ response choice is selected for **Item 2**, then the HCMSQ SoB score is treated as missing.
- If “I had no opportunity to do moderate physical activity” was selected for **Item 3**, the **Item 3** should be imputed as the mean of Items 1, 2, and 4 collected at the same instrument administration.
 - If any of these three items (1, 2, and 4) are missing, the HCMSQ SoB domain score is treated as missing.
- The HCMSQ SoB domain score is the sum of **Items 1-4**. The potential score ranges 0-18 where lower scores indicate less shortness of breath/better health.

HCMSQv2.0-7d Recall Tiredness Domain Score:

- Code responses to each of Item 5 as follow:

Core Symptom	Item	Question	Response Options
Tiredness	5	Were you tired during the past 7 days?	0 = Not at all 1 = Mildly 2 = Moderately 3 = Severely 4 = Very Severely

- The HCMSQ tiredness domain score is the score for **Item 5**. The potential score ranges 0-4 where lower scores indicate less tiredness/better health.

HCMSQv2.0-7d Recall CV Symptoms Score:

- Code responses to each of **Items 6-8** as follow:

Core Symptom	Item	Question	Response Options
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Heart palpitations	6	Did your heart beat rapidly or flutter (palpitations) during past 7 days?	0 = Not at all 1 = Mildly 2 = Moderately 3 = Severely 4 = Very Severely
Chest pain	7	Did you have chest pain during the past 7 days?	0 = Not at all 1 = Mildly 2 = Moderately 3 = Severely 4 = Very Severely
Dizziness	8	Were you dizzy or lightheaded during the past 7 days?	0 = Not at all 1 = Mildly 2 = Moderately 3 = Severely 4 = Very Severely

- The HCMSQ CV symptoms domain score is the sum of Items 6-8. The potential score ranges 0-12 where lower scores indicate less CV symptoms/better health.
 - If any of these three items (6, 7 or 8) is missing, the daily CV symptoms scores is missing.

HCMSQv2.0-7d Recall Total Score:

- The HCMSQ total score is as the equally weighted sum of the three domain scores, i.e., the sum of the SoB domain score divided by four (items), the tiredness domain score (a single item), and the CV symptom domain score divided by three (items), if all three domain scores are calculated; otherwise, the HCMSQ total score is missing. The potential range of scores is 0–12.5, with lower scores indicating a lower presence of symptoms overall/better health.

- $$\frac{\text{HCMSQ SoB domain score}}{4 \text{ (items)}} + \frac{\text{HCMSQ Tiredness domain score}}{1 \text{ (item)}} + \frac{\text{HCMSQ CV Symptoms domain score}}{3 \text{ (items)}}$$

HCMSQv2.0-7d Recall Syncope

- The HCMSQ syncope domain score for syncope is the score (yes=1/no=0) for item 9 (syncope) over the past 7 days. It is kept as additional information but excluded from the HCMSQ Total Score.