



SPIROMICS - HEART FAILURE INSTRUCTIONS FOR KC CARDIOMYOPATHY FORM KCC, VERSION 1.0, QUESTION BY QUESTION (QxQ)

I. GENERAL INSTRUCTIONS

The SPIROMICS-HF KC Cardiomyopathy Form (KCC) is completed during the participant's SPIROMICS-HF study visit after they have been consented into SPIROMICS-HF. For each item, have the participant select the answer that best describes their experience.

Header Information: The header information consists of key fields which uniquely identify each recorded instance of a form. For the Event field, record if this is happening at Visit 5 or another event.

0a. Date of Collection: Record the date the data was collected or abstracted. Select the date from the pop-up calendar in the data management system (DMS) or type the date in the space provided. Dates should be entered in the mm/dd/yyyy format.

0b. Staff Code: Record the SPIROMICS staff code of the person who collected or abstracted the data. This code is assigned to each person at each site by the GIC. If you do not have a staff code and are collecting SPIROMICS data please contact the GIC in order to receive your own individual staff code.

II. DETAILED INSTRUCTIONS FOR EACH ITEM

Please answer every question on this form.

Read out loud to the participant the script at the top of the form, then have the participant answer the following questions.

- Item 1. **Showering or bathing:** Select only one option from the possible six choices. Read the choices aloud and have the participant choose the best answer to describe how much they have been limited by heart failure (shortness of breath or fatigue) in their ability to shower or bathe **over the past 2 weeks**.
- Item 2. **Walking 1 block on level ground:** Select only one option from the possible six choices. Read the choices aloud and have the participant choose the best answer to describe how much they have been limited by heart failure (shortness of breath or fatigue) in their ability to walk 1 block on level ground **over the past 2 weeks**.
- Item 3. **Hurrying or jogging:** Select only one option from the possible five choices. Read the choices aloud and have the participant choose the best answer to describe how much they have been limited by heart failure (shortness of breath or fatigue) in their ability to hurry or jog (as if to catch a bus?) **over the past 2 weeks**.
- Item 4. **Swelling in feet, ankles or legs:** Select only one option from the possible five choices. Read the question and choices aloud and have the participant choose the

best answer to describe how many times **over the past 2 weeks** they had swelling in their feet, ankles or legs when they woke up in the morning.

- Item 5. **Fatigue:** Select only one option from the possible seven choices. Read the question and choices aloud and have the participant choose the best answer to describe how many times, on average, **over the past 2 weeks**, fatigue has limited their ability to do what they wanted.
- Item 6. **Shortness of breath:** Select only one option from the possible seven choices. Read the question and choices aloud and have the participant choose the best answer to describe how many times, on average, **over the past 2 weeks**, shortness of breath has limited their ability to do what they wanted.
- Item 7. **Sleeping with shortness of breath:** Select only one option from the possible five choices. Read the question and choices aloud and have the participant choose the best answer to describe how many times **over the past 2 weeks** they have been forced to sleep sitting up in a chair or with at least 3 pillows to prop them up because of shortness of breath.
- Item 8. **Enjoyment of life:** Select only one option from the possible five choices. Read the question and choices aloud and have the participant choose the best answer to describe how much their heart failure (shortness of breath or fatigue) has limited their enjoyment of life **over the past 2 weeks**.
- Item 9. **Rest of life:** Select only one option from the possible five choices. Read the question and choices aloud and have the participant choose the best answer to describe how they would feel if they had to spend the rest of their life with their heart failure (shortness of breath or fatigue) the way it is **right now**.

For items 10 – 12, read out loud to the participant the preceding question and statement, then have the participant answer the following questions.

- Item 10. **Hobbies, recreational activities:** Select only one option from the possible six choices. Read the choices aloud and have the participant choose the best answer to describe how much their heart failure (shortness of breath or fatigue) has limited their participation in hobbies and/or recreational activities **over the past 2 weeks**.
- Item 10. **Working or doing household chores:** Select only one option from the possible six choices. Read the choices aloud and have the participant choose the best answer to describe how much their heart failure (shortness of breath or fatigue) has limited their participation in work or doing household chores **over the past 2 weeks**.
- Item 12. **Visiting family or friends outside of home:** Select only one option from the possible six choices. Read the choices aloud and have the participant choose the best answer to describe how much their heart failure (shortness of breath or fatigue) has limited their participation in visiting family or friends outside of the participant's home **over the past 2 weeks**.

Save and close the form.