1.8 Patient Registry Status Form

Please use this form to record the date of transfer if a patient transfers their care to another hospital. Also, use this form if a patient revokes their informed consent.

Patient Transferred?: Transferred care to another hospital (patient followed exclusively at another hospital).

Yes/No

If Yes, Date transferred care: Enter as **MM/DD/YYYY**.

If Yes, Transferring Hospital: Select MedaMACS transferring hospital from the list below. All eligible MedaMACS hospitals will appear in the drop down box.

Withdrawn Consent?: Patient withdraws consent and therefore no more clinical data is to be collected.

Yes/No

If Yes, Date withdrawn: Enter as **MM/DD/YYYY**.

1.9 Death Form

The **Death Form** is to be collected at time of death.

Enter **Death date:** In **MM/DD/YYYY** format.

Location of death: Select whether patient was in or out of hospital at time of death. If location was not known, select Unknown.

In hospital
Out of hospital
Unknown

Timing of death: Select one of the timings of death: Expected, Unexpected or the timing of death is Unknown.

Expected
Unexpected
Unknown

Primary cause of Death: Many of the causes of death also represent an adverse event. Please complete the associated adverse event form. Primary Cause of Death to be assigned by the PI. Select one primary cause of death from the list below:

Respiratory
- Venous thromboembolism event
- Respiratory failure
- Pulmonary, other
  - If other, **Specify:** Please specify in text box.

Circulatory
- Arterial Non-CBS thromboembolism
- Myocardial infarction
- Myocardial rupture
- Ruptured aortic aneurysm
- Right heart failure
- Major bleeding
- Cardiac arrhythmia
- Hemolysis
- Hypertension
- Sudden unexplained death
- CHF
- Heart disease
- End stage cardiomyopathy
- Ischemic cardiomyopathy
- Cardiovascular, other
  - If other, **Specify:** Please specify in text box.

Digestive
- Hepatic dysfunction
- Renal dysfunction
- GI disorder
- Fluid/electrolyte disorder
- Pancreatitis

Nervous System

Neurological dysfunction
Psychiatric episode/suicide

Other Causes

MSOF
Withdrawal of support, specify
If **Specify:** Please specify in text box.
Major infection
Trauma/accident, specify
If **Specify:** Please specify in text box.
Cancer, specify

If **Cancer**, specify
CNS
GI
Lymph
ENT
Pulmonary
Renal
Breast
Reproductive
Skin
Unknown
Other:
If Other, **Specify:** Please specify in text box.

1.10 Adverse Events

There are 3 major adverse events which have a form associated with the adverse event: Infection, Bleeding and Neurological Dysfunction.

AE Infection

The **Adverse Event: Major Infection Form** is to be collected at time of event.

Major Infection: Was there a major infection?

Yes
No
Unknown

Major Infection Information

A clinical infection accompanied by pain, fever, drainage and/or leukocytosis that is treated by anti-microbial agents (non-prophylactic). A positive culture from the infected site or organ should be present unless strong clinical evidence indicates the need for treatment despite negative cultures. The general categories of infection are listed below:

Localized Non-Device Infection
localized to any organ system or region (e.g. mediastinitis) without evidence of systemic involvement (See sepsis definition), ascertained by standard clinical methods and either associated with evidence of bacterial, viral, fungal or protozoal infection, and/or requiring empirical treatment.

Sepsis
Evidence of systemic involvement by infection, manifested by positive blood cultures
and/or hypotension.

D

Date of onset: Enter the date of onset of adverse event in **MM/DD/YYYY** format.

Did this infection contribute to death? Enter **Yes** if this infection contributed to the death of this patient. Enter **No** if this infection did not contribute to the death of this patient. If unknown, select **Unknown.**

Yes
No
Unknown

Location of patient: Select whether patient was in or out of hospital at time of adverse event. If location was unknown, select **Unknown**.

In hospital
Out of hospital
Unknown

Location of Infection: Check all that apply

- Positive blood cultures
- Line Sepsis
- Pulmonary
- Urinary tract
- Peripheral wound
- G.I.
- Endocarditis
- Pacer/ICD
- Unknown
- Other
  - **If Other, specify**: Please specify in text box.

Type of infection: Select one of the following types of infection:

- Bacterial
- Fungal
- Viral
- Protozoan
- Unknown

Was antibiotic therapy an intervention for this adverse advent?

- Yes
- No
- Unknown

If Yes, **What was the route?**

- IV
- Oral
- Unknown

Was surgery an intervention for this adverse event?

- Yes
- No
- Unknown

AE Neurological Dysfunction

The **Adverse Event: Neurological Dysfunction Form** is to be collected at time of event.

Neurological Dysfunction: Was there a neurological dysfunction?

Yes
No
Unknown

Neurological Dysfunction

Any new, temporary or permanent, focal or global neurological deficit ascertained by a standard neurological examination (administered by a neurologist or other qualified physician and documented with appropriate diagnostic tests and consultation note). The examining physician will distinguish between a transient ischemic attack (TIA), which is fully reversible within 24 hours (and without evidence of infarction), and a stroke, which lasts longer than 24 hours (or less than 24 hours if there is evidence of infarction). Each neurological event must be subcategorized as:

1. **Transient Ischemic Attack** - Acute event that resolves completely within 24 hours with no evidence of infarction.
2. **Ischemic or Hemorrhagic Cerebrovascular Accident/CVA** - Event that persists beyond 24 hours or less than 24 hours associated with infarction on an imaging study.

Date of onset: Enter the date of onset of adverse event in **MM/DD/YYYY** format.

Location of patient: Select whether patient was in or out of hospital at time of adverse event. If location was unknown, select **Unknown**.

In hospital
Out of hospital
Unknown

Neurological dysfunction categories: Select one of the neurological dysfunction categories. If Neurological Dysfunction - Other is selected, type in the specification in the block provided.

TIA
CVA

If CVA, Type of CVA:

Ischemic
Hemorrhagic

If CVA, Stroke severity:
- Left-sided weakness
- Right-sided weakness
- Left-sided paralysis
- Right-sided paralysis
- Speech deficit
- Altered mental status
- Coma
- Other
  - **If Other**, **Specify:** Please specify in text box.

Seizure

Encephalopathy

Encephalopathy type:
- Metabolic
- Anoxic
- Traumatic
- Unknown
- Other
  - **If Other**, **Specify:** Please specify in text box.

Confusion

Did this neurological dysfunction contribute to death?: If this adverse event caused or contributed to this patient's death, select **Yes.** If this adverse event did not cause or contribute to this patient's death, select **No.** If unknown, select **Unknown.**

Yes
No
Unknown

Anticoagulant therapy at time of event: If anticoagulant therapy was used at the time of this event, check all therapies that apply. If **Other, specify** is selected, type in the specification in the block provided.

Warfarin
Heparin
Lovenox
Dextran
Ticlopidine
Hirudin
Aspirin
Dipyridamole
Clopidogrel (plavix)
Argatroban
Bivalirudin
Lepirudin
Ximelagatran
Fondaparinux
None
Other
- **If Other, Specify:** Please specify in text box.

AE Major Bleeding

The **Adverse Event: Major Bleeding Form** is to be collected at time of event.

Major Bleeding: Was there a major bleeding event?

Yes
No
Unknown

Major Bleeding

An episode of **suspected internal or external bleeding** that results in one or more of the following:

1. **Death,**
2. **Re-operation,**
3. **Hospitalization**
4. **Transfusion of red blood cells**

Note: Hemorrhagic stroke is considered a neurological event and not as a separate bleeding event.

Date of onset: Enter date of bleeding episode onset as **MM/DD/YYYY**.

Location of patient: Select whether patient was in or out of hospital at time of adverse event. If location was unknown, select **Unknown**.

In hospital
Out of hospital
Unknown

Result: Did the major bleeding episode result in one or more of the following? Check all that apply.

Episode resulted in death (fill out form)
Episode resulted in Operation
Episode resulted in hospitalization (currently in the hospital or re-hospitalized)
Episode resulted in transfusion(s) for bleeding episode

Source/cause/location of bleeding: Check all that apply.

- Pleural space
- Intra-abdominal
- Intra-thoracic
- Retroperitoneal
- Pulmonary
- Urinary tract
- GI: Upper gastrointestinal (esophagus, stomach, duodenum, small bowel)
- GI: Lower gastrointestinal (colon, rectum, anus)
- GI: unknown, but guaiac positive stools
- ENT
- Other

INR: Enter value of INR. If **Unknown** or **Not done**, please check corresponding box.

Anticoagulant therapy at time of event: If anticoagulant therapy was used at the time of this event, check all therapies that apply. If **Other, specify** is selected, type in the specification in the block provided.

Warfarin
Heparin
Lovenox
Dextran
Ticlopidine
Hirudin
Aspirin
Dipyridamole
Clopidogrel (plavix)
Argatroban
Bivalirudin
Lepirudin
Ximelagatran
Fondaparinux
None
Other

If Other, Specify: Please specify in text box.

Other Adverse Events

Other Events: Were there any other adverse events? ex: Cardiac arrhythmias, Myocardial infarctions, Psychiatric episode, Respiratory failure, Venous thromboembolism, Arterial Non-CNS thromboemoblic event.

Yes
No

Cardiac Arrhythmias

Documented Arrhythmia: Did a documented arrhythmia result in clinical compromise since last MedaMACS report/last followup?

Yes
No
Unknown

Cardiac Arrhythmias

Any documented arrhythmia that results in clinical compromise (e.g., oliguria, pre-syncope or syncope) that requires hospitalization or occurs during a hospital stay. Cardiac arrhythmias are classified as 1 of 2 types:

1. Sustained ventricular arrhythmia requiring defibrillation or cardioversion.
2. Sustained supraventricular arrhythmia requiring drug treatment or cardioversion.

Date of event: Enter the date of the event in **MM/DD/YYYY** format. If **Unknown** please check the corresponding box.

Type of arrhythmia: Enter the type of arrhythmia from selection below:

Sustained ventricular arrhythmia requiring defibrillation or cardioversion (ventricular)

Sustained supraventricular arrhythmia requiring drug treatment or cardioversion (atrial)

Unknown

Myocardial Infarction

Myocardial Infarction: Did a myocardial infarction occur since last MedaMACS report/last followup?

Yes
No
Unknown

Myocardial Infarction

Peri-Operative Myocardial Infarction
The clinical suspicion of myocardial infarction together with CK-MB or Troponin > 10 times the local hospital upper limits of normal, together with ECG findings consistent with acute myocardial infarction.

Non-Perioperative Myocardial Infarction
The presence of two of the following three criteria:

1. Chest pain which is characteristic of myocardial ischemia,
2. ECG with a pattern or changes consistent with a myocardial infarction, and

Troponin or CK (measured by standard clinical pathology/laboratory medicine methods) greater than the normal range for the local hospital with positive MB fraction (≥ 3% total CK). This should be accompanied by a new regional LV or RV wall motion abnormality on a myocardial imaging study.

Date of Myocardial Infarction: Enter the date of the event in **MM/DD/YYYY** format. If **Unknown** please check the corresponding box.

What was the cause of the myocardial infarction?

Other cardiac cause (specify)
Specify:

Non-cardiac cause (specify)
Specify:

Elective procedure (specify)
Specify:

Psychiatric Episode

Psychiatric Episode: Did a disturbance in thinking, emotion or behavior that required intervention occur in patient since last MedaMACS report/last followup?

Yes
No
Unknown

Psychiatric Episode

Disturbance in thinking, emotion or behavior that causes substantial impairment in functioning or marked subjective distress requiring intervention. Intervention is the addition of new psychiatric medication, hospitalization, or referral to a mental health professional for treatment. Suicide is included in this definition.

Enter date of Psychiatric Episode: in **MM/DD/YYYY** format. If **Unknown** please check the corresponding box.

Respiratory Failure

Respiratory Failure: Did an impairment of respiratory function requiring intubation or mechanical ventilation occur since last MedaMACS report/last followup?

Yes
No
Unknown

Respiratory Failure

Impairment of respiratory function requiring reintubation, tracheostomy. This excludes intubation for re-operation or temporary intubation for diagnostic or therapeutic procedures.

Date of Respiratory Failure: in **MM/DD/YYYY** format. If **Unknown** or **Ongoing** please check the corresponding box.

Intubation duration (in days): If **Unknown** or **Ongoing** please check the corresponding box.

Was a tracheotomy performed?

Yes
No
Unknown

Venous Thromboembolism

Venous Thromboembolism: Evidence of Venous Thromboembolic event since last MedaMACS report/last followup?

Yes
No
Unknown

Venous Thromboembolism

Evidence of venous thromboembolic event (e.g. deep vein thrombosis, pulmonary embolism) by standard clinical and laboratory testing.

Thromboembolism Type: Check all that apply.

Deep Vein thrombosis
If Checked, **Enter date:** in **MM/DD/YYYY** format. If **Unknown** please check the corresponding box.
Pulmonary Embolis
If Checked, **Enter date:** in **MM/DD/YYYY** format. If **Unknown** please check the corresponding box.
Other
If selected, **Specify:** Please specify in text box.
Unknown

Anticoagulant therapy at time of event: If anticoagulant therapy was used at the time of this event, check all therapies that apply. If **Other, specify** is selected, type in the specification in the block provided.

- Warfarin
- Heparin
- Lovenox
- Aspirin
- Dipyridamole
- Clopidogrel (plavix)
- Argatroban
- Bivalirudin
- Fondaparinux
- Dextran
- Ticlopidine
- Hirudin
- Lepirudin
- Ximelagatran
- None
- Unknown
- Other

If Other, Specify: Please specify in text box.

Arterial Non-CNS Thromboembolic Event

Arterial Non-CNS Thromboembolic Event: Did an acute perfusion deficit in any non-cerebrovascular organ system occur since last MedaMACS report/last followup?

- Yes
- No
- Unknown

Arterial Non-CNS Thromboembolic Event

An acute systemic arterial perfusion deficit in any non-cerebrovascular organ system due to thromboembolism confirmed by one or more of the following:

1) Standard clinical and laboratory testing
2) Operative findings
3) Autopsy findings

Date of Arterial Non-CNS Thromboembolic Event: in **MM/DD/YYYY** format. If **Unknown** please check the corresponding box.

Select a location:

Pulmonary
Splenic
Limb
Renal
Hepatic
Unknown
Other

If **Other, Specify:** Please specify in text box.

Confirmation source:

Standard clinical and laboratory testing
Operative findings
Autopsy finding
Unknown
Other

If **Other, Specify:** Please specify in text box.

Anticoagulant therapy at time of event: If anticoagulant therapy was used at the time of this event, check all therapies that apply. If **Other, specify** is selected, type in the specification in the block provided.

Warfarin
Heparin
Lovenox
Aspirin
Dipyridamole
Clopidogrel (plavix)
Argatroban
Bivalirudin
Fondaparinux
Dextran
Ticlopidine
Hirudin
Lepirudin
Ximelagatran
None
Unknown
Other

If **Other, Specify:** Please specify in text box.

Other Adverse Event

Did another adverse event occur that was not listed above?:

Yes
No

Other Adverse Event
An event that causes clinically relevant changes in the patient's health (e.g. cancer).

Date of Event: in **MM/DD/YYYY** format. If **Unknown** please check the corresponding box.

Describe the Event: Enter other serious adverse events that occurred since last report/last follow-up into the block provided.

1.11 Quality of Life

Quality of life is to be measured by the **EuroQol (EQ-5D)** and the **Kansas City Cardiomyopathy Questionnaire (KCCQ)** instruments, which are provided on the INTERMACS website www.intermacs.org, then click on MedaMACS.

Only adult patients (age 19 years and older) will be asked to complete these instruments.

All adult patients should complete the EuroQol (EQ-5D) and KCCQ.

- The EuroQol (EQ-5D) should be completed at clinical enrollment, 1 month visit, 1 year visit and 2 year visit. A phone version of the EuroQol (EQ-5D) should be administered at 6 months and 18 months.
- The KCCQ will be administered at clinic enrollment, 1 month, 1 year and 2 year follow-up visits.

Data collection

The EuroQol (EQ-5D) and KCCQ are administered by research or clinical coordinators as designated by each participating medical center. The EuroQol (EQ-5D) and KCCQ instruments can be printed from the INTERMACS website www.intermacs.org, click on MedaMACS.

Instrument Administration

- The patient is to complete the EuroQol (EQ-5D) and KCCQ instruments via self-report independently.

If the patient is unable to complete the EuroQol (EQ-5D) and KCCQ instruments, the coordinator or a family member is to read the questions to the patient and complete the instruments documenting the patient's responses. Indicate on the instruments that the EuroQol (EQ-5D) and KCCQ were self-administered or administered verbally by another.

- There should be no coaching regarding responses.
- Enter the patient's answers from the paper form into the database through www.intermacs.org, click on MedaMACS.

Data Screening

- The EuroQol (EQ-5D) and KCCQ are to be reviewed for missing or unclear data at the time of instrument completion. Corrections must be made with the patient at that time.

Non Submission of EuroQol (EQ-5D) and KCCQ

- For patients who do not complete the EuroQol (EQ-5D) or KCCQ, please enter reason as to why the EuroQol (EQ-5D) or KCCQ were not completed in the missing data survey.

EuroQol (EQ-5D)

Did the patient complete a EuroQol (EQ-5D) form: Enter **Yes or No**

Yes/No

If No, Please select a reason why the EuroQol (EQ-5D) was not completed: Select the reason for non-completion of the EuroQol (EQ-5D) from the drop down list provided.

Too sick
Too tired
Too stressed, anxious, and/or depressed
Can't concentrate
No time/to busy
Too much trouble/don't want to be bothered/not interested
Unwilling to complete instruments, no reason given
Unable to read English and/or illiterate
Administrative (check specific reason below)

If Administrative: Select a specific reason:
- No time, coordinator too busy to administer self-report instruments
- Coordinator forgot to administer self-report instruments
- Unable to contact patient face-to-face or per telephone
- Patient did not return mailed self-report instruments within the window for instrument completion
- Other reason, specify

If Other reason, specify: Please specify in text box.

If Yes, enter the patients answers from the EuroQol (EQ-5D) printed form into the MedaMACS application.

Mobility:
- I have no problems in walking about
- I have some problems in walking about
- I am confined to bed
- Unknown

Self-care:
- I have no problems with self-care
- I have some problems washing or dressing myself
- I am unable to wash or dress myself
- Unknown

Usual activities: (e.g. work, study, housework, family or leisure activities)
- I have no problem with performing my usual activities
- I have some problems with performing my usual activities
- I am unable to perform my usual activities
- Unknown

Pain/Discomfort:
- I have no pain or discomfort
- I have moderate pain or discomfort
- I have extreme pain or discomfort
- Unknown

Anxiety/Depression:
- I am not anxious or depressed
- I am moderately anxious or depressed
- I am extremely anxious or depressed
- Unknown

Patient Visual Analog Status (VAS): Enter _____. (0 = Worst, 100 = Best) If Unknown, please select the corresponding box.

Which of the following best describes your main activity?:

Actively working – Full Time
Actively working – Part Time
Too sick to work (disabled) – Full Time
Too sick to work (disabled) – Part Time
Retired – Full Time
Retired – Part Time
Keeping house – Full Time
Keeping house – Part Time
Student – Full Time
Student – Part Time
Seeking work – Full Time
Seeking work – Part Time
Other, specify – Full Time
Other, specify – Part Time

If Other, specify: Please specify in text box.

How many of your close friends or relatives do you see in person, speak to on the telephone, or contact via the Internet at least once a month? (Please count each person one time)

How much stress do you feel you've been under during the past one month, related to your health issues? (1 = No stress, 10 = Very much stress)

How well do you feel you've been coping with or handling your stress during the past one month, related to your health issues? (1 = Coping poorly, 10 = Coping very well)

How confident are you that you can do the tasks and activities needed to manage your heart failure so as to reduce how much having heart failure affects your everyday life? (1 = Not at all confident, 10 = Totally confident)

How satisfied are you with the results of your therapy for heart failure during the past six months? (1 = Not satisfied at all, 10 = Very satisfied)

Kansas City Cardiomyopathy Questionnaire (KCCQ)

Did the patient complete a KCCQ form: Enter **Yes or No.**

Yes/No

If No, Please select a reason why the KCCQ was not completed:
Select the reason for non-completion of the KCCQ from the drop down list provided.

Too sick
Too tired
Too stressed, anxious, and/or depressed
Can't concentrate
No time/to busy
Too much trouble/don't want to be bothered/not interested
Unwilling to complete instruments, no reason given
Unable to read English and/or illiterate
Administrative (check specific reason below)

If Administrative, Check specific reason below:

No time, coordinator too busy to administer self-report instruments
Coordinator forgot to administer self-report instruments
Unable to contact patient face-to-face or per telephone
Patient did not return mailed self-report instruments within the window for instrument completion
Other reason, specify

If Other reason, specify: Please specify in text box.

If **Yes,** enter the patients answers from the KCCQ printed form into the MedaMACS application.

THE KANSAS CITY CARDIOMYOPATHY QUESTIONNAIRE:
The following questions refer to your heart failure and how it may affect your life. Please read and complete the following questions. There is no right or wrong answer. Please mark the answer that best applies to you.

1. **Heart Failure** affects different people in different ways. Some feel shortness of breath while others feel fatigue. Please indicate how much you are limited by **heart failure** (*shortness of breath or fatigue*) in your ability to do the following activities over the past 2 weeks.

Dressing yourself

Not at all limited
Slightly limited
Moderately limited
Quite a bit limited
Extremely limited
Limited for other reasons or did not do the activity
Unknown

† † † † † †

Showering/Bathing

Not at all limited
Slightly limited
Moderately limited
Quite a bit limited
Extremely limited
Limited for other reasons or did not do the activity
Unknown

Walking 1 block on level ground

Not at all limited
Slightly limited
Moderately limited
Quite a bit limited
Extremely limited
Limited for other reasons or did not do the activity
Unknown

Doing yard work, housework or carrying groceries

Not at all limited
Slightly limited
Moderately limited
Quite a bit limited
Extremely limited
Limited for other reasons or did not do the activity
Unknown

Climbing a flight of stairs without stopping

Not at all limited
Slightly limited
Moderately limited
Quite a bit limited
Extremely limited
Limited for other reasons or did not do the activity
Unknown

Hurrying or jogging (as if to catch a bus)

Not at all limited
Slightly limited
Moderately limited
Quite a bit limited
Extremely limited
Limited for other reasons or did not do the activity
Unknown

2. Compared with 2 weeks ago, have your symptoms of **heart failure** (*shortness of breath, fatigue or ankle swelling*) changed? My symptoms of **heart failure** have become…

Much worse
Slightly worse
Not changed
Slightly better
Much better
I've had no symptoms over the last 2 weeks
Unknown

3. Over the past 2 weeks, how many times did you have **swelling** in your feet, ankles or legs when you woke up in in the morning?

Every morning
3 or more times a week, but not every day
1-2 times a week
Less than once a week
Never over the past 2 weeks
Unknown

4. Over the past 2 weeks, how much has **swelling** in your feet, ankles or legs bothered you?

Extremely bothersome
Quite a bit bothersome
Moderately bothersome
Slightly bothersome
Not at all bothersome
I've had no swelling
Unknown

5. Over the past 2 weeks, on average, how many times has **fatigue** limited your ability to do what you want?

All the time
Several times per day
At least once a day
3 or more times per week, but not every day
1-2 times per week
Less than once a week
Never over the past 2 weeks
Unknown

6. Over the past 2 weeks, how much has your **fatigue** bothered you?

Extremely bothersome
Quite a bit bothersome
Moderately bothersome
Slightly bothersome
Not at all bothersome
I've had no fatigue
Unknown

7. Over the past 2 weeks, on average, how many times has **shortness of breath** limited your ability to do what you wanted?

All the time

Several times per day
At least once a day
3 or more times per week, but not every day
1-2 times per week
Less than once a week
Never over the past 2 weeks
Unknown †

8. Over the past 2 weeks, how much has your shortness of breath bothered you?
Extremely bothersome
Quite a bit bothersome
Moderately bothersome
Slightly bothersome
Not at all bothersome
I've had no shortness of breath
Unknown †

9. Over the past 2 weeks, on average, how many times have you been forced to sleep sitting up in a chair or with at least 3 pillows to prop you up because of **shortness of breath**?
Every night
3 or more times a week, but not every day
1-2 times a week
Less than once a week
Never over the past 2 weeks
Unknown †

10**. Heart Failure** symptoms can worsen for a number of reasons. How sure are you that you know what to do, or whom to call, if your **heart failure** gets worse?
Not at all sure
Not very sure
Somewhat sure
Mostly sure
Completely sure
Unknown †

11. How well do you understand what things you are able to do to keep your **heart failure** symptoms from getting worse? (*for example, weighing yourself, eating a low salt diet, etc*.)
Do not understand at all
Do not understand very well
Somewhat understand
Mostly understand
Completely understand
Unknown

12. Over the <u>past 2 weeks</u>, how much has your **heart failure** limited your enjoyment of life?

It has extremely limited my enjoyment of life
It has limited my enjoyment of life quite a bit
It has moderately limited my enjoyment of life
It has slightly limited my enjoyment of life
It has not limited my enjoyment of life at all
Unknown

† † † † †

13. If you had to spend the rest of your life with your **heart failure** the way it is <u>right now</u>, how would you feel about this?

Not at all satisfied
Mostly dissatisfied
Somewhat satisfied
Mostly satisfied
Completely satisfied
Unknown † † † † †

14. Over the <u>past 2 weeks</u>, how often have you felt discouraged or down in the dumps because of your **heart failure**?

I felt that way all the time
I felt that way most of the time
I occasionally felt that way
I rarely felt that way
I never felt that way
Unknown

† † † † †

15. How much does your **heart failure** affect your lifestyle? Please indicate how your **heart failure** may have limited your participation in the following activities <u>over the past 2 weeks</u>.

Hobbies, recreational activities

Not at all limited
Slightly limited
Moderately limited
Quite a bit limited
Extremely limited
Limited for other reasons or did not do the activity
Unknown

Working or doing household chores

Not at all limited
Slightly limited
Moderately limited
Quite a bit limited
Extremely limited
Limited for other reasons or did not do the activity
Unknown

†

Visiting family or friends out of your home

Not at all limited
Slightly limited
Moderately limited
Quite a bit limited
Extremely limited
Limited for other reasons or did not do the activity
Unknown

Intimate relationships with loved ones

Not at all limited
Slightly limited
Moderately limited
Quite a bit limited
Extremely limited
Limited for other reasons or did not do the activity
Unknown

Developed by John Spertus et al., Mid America Heart Institute, Saint Luke's Hospital, Kansas City, MO.

APPENDIX A: MedaMACS SURVEY INSTRUMENTS

Physician Questionnaire:
This is for the physician to complete!

Clinical Enrollment Visit Only

1. How long has patient been under care of your heart failure program?
   < 3 months
   3-12 months
   1-2 years
   > 2 years
   Unknown

2. Which best describes the route of presentation?
   New onset event or diagnosis within your institution
   Unspecified evaluation of severe heart failure
   Cardiac transplant and/or VAD evaluation
   Unknown

3. Who referred the patient?
   Local internist
   Local cardiologist
   Cardiac surgeon
   Self-referral
   Unsure
   Not applicable
   Unknown
   Other

1.12 Seattle Heart Failure Score

Please calculate the Seattle Heart Failure Score at:

http://depts.washington.edu/shfm/