

PCDM Long:

The PCDM Long Dataset records all time varying values, which is the survey results as well as the case report form.

Var Num	Var Name	Variable Description	Value Codes
1	pt_id	De-identified patient ID	Links to pcdm_wide
2	surv_day	Days relative to baseline the survey was completed	
3	surv_version	Survey category	Baseline, 3months, 6months, Final
KCCQ The Kansas City Cardiomyopathy Questionnaire Variables. This survey was given at all sites and at all surv_Version time points (missing data indicates failure to obtain survey at that time point). See the survey for question text. The specific variables start at 1 and go in the order on the survey. Depending on the question, this may be bad to good or good to bad.			
4	KCCQ01a	How much are you limited by heart failure (shortness of breath or fatigue) in your ability to <i>dress yourself</i> over the past two weeks.	1=Extremely Limited, 2=Quite a bit limited,3=Moderately Limited, 4=Slightly limited, 5=not at all limited, 6=limited for other reasons or did not do the activity
5	KCCQ01b	How much are you limited by heart failure (shortness of breath or fatigue) in your ability to <i>shower/bathe</i> over the past two weeks.	1=Extremely Limited, 2=Quite a bit limited,3=Moderately Limited, 4=Slightly limited, 5=not at all limited, 6=limited for other reasons or did not do the activity
6	KCCQ01c	How much are you limited by heart failure (shortness of breath or fatigue) in your ability to <i>walk 1 block on level ground</i> over the past two weeks.	1=Extremely Limited, 2=Quite a bit limited,3=Moderately Limited, 4=Slightly limited, 5=not at all limited, 6=limited for other reasons or did not do the activity
7	KCCQ01d	How much are you limited by heart failure (shortness of breath or fatigue) in your ability to <i>do yardwork, housework, or carry groceries</i> over the past two weeks.	1=Extremely Limited, 2=Quite a bit limited,3=Moderately Limited, 4=Slightly limited, 5=not at all limited, 6=limited for other reasons or did not do the activity
8	KCCQ01e	How much are you limited by heart failure (shortness of breath or fatigue) in your ability to <i>climb a flight of stairs without stopping</i> over the past two weeks.	1=Extremely Limited, 2=Quite a bit limited,3=Moderately Limited, 4=Slightly limited, 5=not at all limited, 6=limited for other reasons or did not do the activity
9	KCCQ01f	How much are you limited by heart failure (shortness of breath or fatigue) in your ability to <i>hurry or jog (as if to catch a bus)</i> over the past two weeks.	1=Extremely Limited, 2=Quite a bit limited,3=Moderately Limited, 4=Slightly limited, 5=not at all limited, 6=limited for other reasons or did not do the activity

10	KCCQ02	Compared with 2 weeks ago, have your symptoms of heart failure (shortness of breath, fatigue, ankle swelling) changed? My symptoms of heart failure have become....	1=Much worse, 2=slightly worse,3=Not changed, 4=slightly better,5=much better, 6=no symptoms
11	KCCQ03	Over the <u>past 2 weeks</u> , how many times did you have swelling in your feet, ankles or legs when you woke up in the morning?	1=Every morning, 2=3 or more times per week, but not every day, 3=1-2 times a week, 4=Less than once a week, 5=Never over the past 2 weeks
12	KCCQ04	Over the <u>past 2 weeks</u> , how much has swelling in your feet, ankles or legs bothered you? It has been...	1=Extremely bothersome, 2=Quite a bit bothersome, 3=Moderately bothersome, 4=Slightly bothersome, 5=Not at all bothersome, 6=I've had no swelling
13	KCCQ05	Over the <u>past 2 weeks</u> , on average, how many times has fatigue limited your ability to do what you want?	1=All of the time, 2=Several times per day, 3=At least once a day, 4=3 or more times per week but not every day, 5=1-2 times per week, 6=Less than once a week, 6=Never over the past 2 weeks
14	KCCQ06	Over the <u>past 2 weeks</u> , how much has your fatigue bothered you?	1=Extremely bothersome, 2=Quite a bit bothersome, 3=Moderately bothersome, 4=Slightly bothersome, 5=Not at all bothersome, 6=I've had no fatigue
15	KCCQ07	Over the <u>past 2 weeks</u> , on average, how many times has shortness of breath limited your ability to do what you wanted?	1=All of the time, 2=Several times per day, 3=At least once a day, 4=3 or more times per week but not every day, 5=1-2 times per week, 6=Less than once a week, 6=Never over the past 2 weeks
16	KCCQ08	Over the <u>past 2 weeks</u> , how much has your shortness of breath bothered you? It has been...	1=Extremely bothersome, 2=Quite a bit bothersome, 3=Moderately bothersome, 4=Slightly bothersome, 5=Not at all bothersome, 6=I've had no shortness of breath
17	KCCQ09	Over the <u>past 2 weeks</u> , 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 ?	1=Every night, 2=3 or more times a week but not everyday, 3=1-2 times a week, 4=Less than once a week, 5=Never over the past 2 weeks
18	KCCQ10	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 you heart failure gets worse?	1=Not at all sure, 2=Not very sure, 3=Somewhat sure, 4=Mostly sure, 5=Completely sure
19	KCCQ11	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.)	1=Do not understand at all, 2=Do not understand very well, 3=Somewhat understand, 4=Mostly understand, 5=Completely understand
20	KCCQ12	Over the <u>past 2 weeks</u> , how much has your heart failure limited your enjoyment of life?	1=It has extremely limited my enjoyment of life, 2=It has limited my enjoyment of life quite a bit, 3=It has moderately limited my enjoyment of life,

			4=It has slightly limited my enjoyment of life, 5=It has not limited my enjoyment of life
21	KCCQ13	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?	1=Not at all satisfied, 2=Mostly dissatisfied, 3=Somewhat satisfied, 4=Mostly satisfied, 5=Completely satisfied
22	KCCQ14	Over the <u>past 2 weeks</u> , how often have you felt discouraged or down in the dumps because of your heart failure ?	1=I felt that way all of the time, 2=I felt that way most of the time, 3=I occasionally felt that way, 4=I rarely felt that way, 5=I never felt that way
23	KCCQ15a	How much does your heart failure limit your participation in <i>hobbies and recreational activities</i> <u>over the past 2 weeks</u> ?	1=Severely limited, 2=Limited quite a bit, 3=Moderately limited, 4=Slightly limited, 5=Did not limit at all, 6=Does not apply or did not do for other reasons
24	KCCQ15b	How much does your heart failure limit your participation in <i>working or doing household chores</i> <u>over the past 2 weeks</u> ?	1=Severely limited, 2=Limited quite a bit, 3=Moderately limited, 4=Slightly limited, 5=Did not limit at all, 6=Does not apply or did not do for other reasons
25	KCCQ15c	How much does your heart failure limit your participation in <i>visiting family or friends out of your home</i> <u>over the past 2 weeks</u> ?	1=Severely limited, 2=Limited quite a bit, 3=Moderately limited, 4=Slightly limited, 5=Did not limit at all, 6=Does not apply or did not do for other reasons
26	KCCQ15d	How much does your heart failure limit your participation in <i>intimate relationships with loved ones</i> <u>over the past 2 weeks</u> ?	1=Severely limited, 2=Limited quite a bit, 3=Moderately limited, 4=Slightly limited, 5=Did not limit at all, 6=Does not apply or did not do for other reasons
27	KCCQPL	Physical Limitations Domain Score (0-100)	See KCCQ scoring guide
28	KCCQSS	symptom stability Domain Score (0-100)	See KCCQ scoring guide
29	KCCQSF	symptom frequency Domain Score (0-100)	See KCCQ scoring guide
30	KCCQSB	symptom burden domain score (0-100)	See KCCQ scoring guide
31	KCCQTS	Total Symptoms Domain Score (0-100)	See KCCQ scoring guide
32	KCCQSE	self efficacy Domain Score (0-100)	See KCCQ scoring guide
33	KCCQQL	Quality of Life Domain (0-100)	See KCCQ scoring guide
34	KCCQSL	social limitation Domain Score (0-100)	See KCCQ scoring guide
35	KCCQOS	Overall Summary (0-100)	See KCCQ scoring guide
36	KCCQCS	Clinical summary Domain Score (0-100)	See KCCQ scoring guide
37	CRF_MI	Prior MI	0=No, 1=Yes
38	CRF_PCI	Prior PCI	0=No, 1=Yes
39	CRF_CABG	Prior CABG	0=No, 1=Yes

40	CRF_ICD	ICD	0=No, 1=Yes
41	CRF_BIV	Bi V Pacemaker	0=No, 1=Yes
42	CRF_PACE	Pacemaker	0=No, 1=Yes
43	CRF_DM	Diabetes	0=No, 1=Yes
44	CRF_HTN	Hypertension	0=No, 1=Yes
45	CRF_TIA	Stroke or TIA	0=No, 1=Yes
46	CRF_COPD	COPD	0=No, 1=Yes
47	CRF_AFIB	Afib or flutter	0=No, 1=Yes
48	CRF_PVD	Peripheral Vascular Disease	0=No, 1=Yes
49	CRF_DEP	History of Depression	0=No, 1=Yes
50	CRF_PTSD	PTSD	0=No, 1=Yes
51	CRF_APNEA	Sleep Apnea	0=No, 1=Yes
52	CRF_SA	History of Alcohol Abuse	0=No, 1=Yes
53	CRF_SAO	Other Substance Abuse	0=No, 1=Yes
54	CRF_CAD	Etiology: CAD/Ischemia	0=No, 1=Yes
55	CRF_ETHTN	Etiology: Hypertension	0=No, 1=Yes
56	CRF_ETVAL	Etiology: Valvular	0=No, 1=Yes
57	CRF_ETIDI	Etiology: Idiopathic/Other	0=No, 1=Yes
58	CRF_ETALC	Etiology: Alcohol	0=No, 1=Yes
59	CRF_EF	Most recent ejection fraction (%; midpoint if range)	
60	CRF_EFCLASS	EF class	1 = Normal, 2=Mild, 3=Moderate, 4=Severe LV Function
61	CRF_EFTYPE	EF assessed by:	1=Echo, 2=Ventriculography
62	CRF_GENDER	Gender	1=Male, 2= Female
63	CRF_RAWH	Race White	0=No, 1=Yes
64	CRF_RABL	Race Black	0=No, 1=Yes
65	CRF_RARAAS	Race Asian or pacific islander	0=No, 1=Yes
66	CRF_RAAI	Race American Indian or Alaskan native	0=No, 1=Yes
67	CRF_RAOT	Race Other	0=No, 1=Yes
68	CRF_ETH	Ethnicity:	1 = Hispanic Origin, 2 = Non-Hispanic Origin
69	CRF_SMOKE	Smoking status	1=Current, 2=Quit < 1 year a go, 3=Quit >= 1 year a go, 4 = Never
70	CRF_NYHA	Current NYHA Class (Assessment)	1, 2, 3, 4
71	CRF_PULSE	Current Vitals: Pulse	BPM

72	CRF_DIA	Current Vitals: Diastolic BP	
73	CRF_SYS	Current Vitals: Systolic BP	
74	CRF_HTFT	Current Vitals: Height feet	
75	CRF_HTIN	Current Vitals: Height inches	
76	CRF_WT	Current Vitals: Weight in lbs	
77	CRF_O2	Current Vitals: Resting O2 Sat %	
78	CRF_EDEMA	Peripheral Edema	0=No, 1=Yes
79	CRF_EDTRACE	For edema:	99 = None, 0=Trace, 1=1+, 2=2+,3=3+,4=4+
80	CRF_PHYS	Physician present at baseline	0=No, 1=Yes
81	CRF_JVD	JVD	
82	CRF_RALES	Presence of rales	1=Yes 2=No
83	CRF_SECR	Serum creatinine	
84	CRF_EGFR	EGFR	
85	CRF_NA	Sodium	
86	CRF_CHOL	Total Cholesterol	
87	CRF_LDL	LDL	
88	CRF_HDL	HDL	
89	CRF_TRIG	Triglycerides	
90	CRF_HG	Hemoglobin	
91	CRF_LYMPH	Percent lymphocytes	
92	CRF_HEMA	Hematocrit	
93	CRF_K	Potassium	
94	CRF_URIC	Uric Acid	
95	CRF_TSH	TSH	
96	CRF_BNP	BNP	
97	CRF_ECGDUR	QRS duration	
98	CRF_ECGTYPE_SINUS	ECG: Sinus rhythm	
99	CRF_ECGTYPE_PACED	ECG: Paced	
100	CRF_ECGTYPE_AFIB	ECG: Atrial Fibrillation	
101	CRF_ECGTYPE_LBBB	ECG: Left bundle branch block	

102	CRF_6MIN	6 minute walk test distance	
Patient Health Questionnaire: This survey is interpreted for depression usually, with low scores meaning less depression risk and high scores means high depression risk			
103	PHQ01	Over the last <u>two weeks</u> , how often have you been bothered by <i>little interest or pleasure in doing things?</i>	0=Not at All, 1=Several Days, 2=More than Half the Days, 3=Nearly Every Day
104	PHQ02	Over the last <u>two weeks</u> , how often have you been bothered by <i>feeling down, depressed, or hopeless?</i>	0=Not at All, 1=Several Days, 2=More than Half the Days, 3=Nearly Every Day
105	PHQ03	Over the last <u>two weeks</u> , how often have you been bothered by <i>trouble falling or staying asleep, or sleeping too much?</i>	0=Not at All, 1=Several Days, 2=More than Half the Days, 3=Nearly Every Day
106	PHQ04	Over the last <u>two weeks</u> , how often have you been bothered by <i>feeling tired or having little energy?</i>	0=Not at All, 1=Several Days, 2=More than Half the Days, 3=Nearly Every Day
107	PHQ05	Over the last <u>two weeks</u> , how often have you been bothered by <i>poor appetite or overeating?</i>	0=Not at All, 1=Several Days, 2=More than Half the Days, 3=Nearly Every Day
108	PHQ06	Over the last <u>two weeks</u> , how often have you been bothered by <i>feeling bad about yourself or that you are a failure or have let yourself or your family down?</i>	0=Not at All, 1=Several Days, 2=More than Half the Days, 3=Nearly Every Day
109	PHQ07	Over the last <u>two weeks</u> , how often have you been bothered by <i>trouble concentrating on things, such as reading the newspaper or watching television?</i>	0=Not at All, 1=Several Days, 2=More than Half the Days, 3=Nearly Every Day
110	PHQ08	Over the last <u>two weeks</u> , how often have you been bothered by <i>moving or speaking so slowly so that other people could have noticed? Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual?</i>	0=Not at All, 1=Several Days, 2=More than Half the Days, 3=Nearly Every Day
111	PHQ09	Over the last <u>two weeks</u> , how often have you been bothered by <i>thoughts that you would be better off dead, or of hurting yourself in some way?</i>	0=Not at All, 1=Several Days, 2=More than Half the Days, 3=Nearly Every Day
112	PHQ10	If you checked off any of the problems on the questionnaire so far, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?	0= Not at all difficult, 1=Somewhat difficult, 2=Very difficult, 3=Extremely difficult
113	PHQSCORE	Overall PHQ Score, sum of phq01-09	If greater than 9, than patient is at risk of depression
Signs and Symptoms Survey:			
114	SS01	Over the past <u>two weeks</u> , how much has <i>chest pain or pressure</i> bothered you?	1=Extremely Bothersome, 2=Quite a bit bothersome, 3=Moderately bothersome, 4=Slightly bothersome, 5=Not at All bothersome, 6=I have not had this symptom

115	SS02	Over the past <u>two weeks</u> , how much has <i>other pain</i> bothered you?	1=Extremely Bothersome, 2=Quite a bit bothersome, 3=Moderately bothersome, 4=Slightly bothersome, 5=Not at All bothersome, 6=I have not had this symptom
116	SS03	Over the past <u>two weeks</u> , how much has <i>dry mouth</i> bothered you?	1=Extremely Bothersome, 2=Quite a bit bothersome, 3=Moderately bothersome, 4=Slightly bothersome, 5=Not at All bothersome, 6=I have not had this symptom
117	SS04	Over the past <u>two weeks</u> , how much has <i>numbness or tingling in your hands and feet</i> bothered you?	1=Extremely Bothersome, 2=Quite a bit bothersome, 3=Moderately bothersome, 4=Slightly bothersome, 5=Not at All bothersome, 6=I have not had this symptom
118	SS05	Over the past <u>two weeks</u> , how much has <i>constipation</i> bothered you?	1=Extremely Bothersome, 2=Quite a bit bothersome, 3=Moderately bothersome, 4=Slightly bothersome, 5=Not at All bothersome, 6=I have not had this symptom
119	SS06	Over the past <u>two weeks</u> , how much has <i>nausea</i> bothered you?	1=Extremely Bothersome, 2=Quite a bit bothersome, 3=Moderately bothersome, 4=Slightly bothersome, 5=Not at All bothersome, 6=I have not had this symptom
120	SS07	Over the past <u>two weeks</u> , how much has <i>cough</i> bothered you?	1=Extremely Bothersome, 2=Quite a bit bothersome, 3=Moderately bothersome, 4=Slightly bothersome, 5=Not at All bothersome, 6=I have not had this symptom
121	SS08	Over the past <u>two weeks</u> , how much has <i>dizziness</i> bothered you?	1=Extremely Bothersome, 2=Quite a bit bothersome, 3=Moderately bothersome, 4=Slightly bothersome, 5=Not at All bothersome, 6=I have not had this symptom
122	SS09	How would you rate your overall <u>quality of life</u> ?	1=Very poor, 2=poor, 3=Fair,4=Good,5=Excellent
123	SS10	Please respond to the following statement: " <u>I Feel at peace</u> "	1=Not at All, 2=A little bit, 3=A moderate amount,4= quite a bit, 5=Completely
124	SSSCORE	Not Populated, don't interpret	
Generalized Anxiety disorder Survey			
125	GAD01	Over the <u>last 2 weeks</u> , how often have you been bothered by <i>feeling nervous, anxious, or on edge</i> ?	0=not at all, 1=Several Days, 2= More than half the Days, 3=Nearly Every Day
126	GAD02	Over the <u>last 2 weeks</u> , how often have you been bothered by <i>not being able to stop or control worrying</i> ?	0=not at all, 1=Several Days, 2= More than half the Days, 3=Nearly Every Day

127	GAD03	Over the <u>last 2 weeks</u> , how often have you been bothered by <i>worrying too much about different things</i> ?	0=not at all, 1=Several Days, 2= More than half the Days, 3=Nearly Every Day
128	GAD04	Over the <u>last 2 weeks</u> , how often have you been bothered by <i>trouble relaxing</i> ?	0=not at all, 1=Several Days, 2= More than half the Days, 3=Nearly Every Day
129	GAD05	Over the <u>last 2 weeks</u> , how often have you been bothered by <i>being so restless that it is hard to sit still</i> ?	0=not at all, 1=Several Days, 2= More than half the Days, 3=Nearly Every Day
130	GAD06	Over the <u>last 2 weeks</u> , how often have you been bothered by <i>becoming easily annoyed or irritable</i> ?	0=not at all, 1=Several Days, 2= More than half the Days, 3=Nearly Every Day
131	GAD07	Over the <u>last 2 weeks</u> , how often have you been bothered by <i>feeling afraid as if something awful might happen</i> ?	0=not at all, 1=Several Days, 2= More than half the Days, 3=Nearly Every Day
132	GAD08	If you checked off <u>any</u> problems, how <u>difficult</u> have these problems made it for you to do your work, take care of things at home, or get along with other people?	0=Not at All Difficult, 1=Somewhat Difficult, 2=Very Difficult, 3=Extremely Difficult
133	GADLEVEL	Not Populated Correctly, do not use	

PCDM Wide:

The PCDM Wide datasets records all time static variables.

Var Num	Var Name	Variable Description	Value Codes
1	pt_id	De-identified patient ID	Links to pcdm_long
2	GENDER	Gender	1=Male, 2=Female
3	ARM	Randomization Arm	Usual Care, Intervention
4	age	Age at enrollment	Ages 90 and over coded as '999'
5	death	death recorded	0=No, 1= Yes
6	time_death	Days to death relative to enrollment date	
7	hosp	hospitalization	0=No, 1=Yes
8	time_hosp	Days to first hospitalization relative to enrollment date	
9	depressed	Depression Risk at baseline based on PHQ9 Score > 9	0=No,1=Yes