

Data Set Name: scdicii_cardiacprocedureform_yr1.sas7bdat

Num	Variable	Type	Len	Format	Informat	Label
1	newid	Char	8	\$8.	\$8.	Subject ID
2	site	Num	8	BEST12.	BEST32.	Site
3	p1f9q00_dtdys	Num	8	BEST12.	BEST32.	Date Form Completed
4	p1f9c0a_dys	Num	8	BEST12.	BEST32.	a. Date of most recent right heart catheterization
5	p1f9qc0__1	Num	8	BEST12.	BEST32.	Most recent right heart catheterization (choice=Report not available)
6	p1f9q001	Num	8	BEST12.	BEST32.	1. LA Volume
7	p1f9q002	Num	8	BEST12.	BEST32.	2. LA Diameter
8	p1f9q002a	Num	8	BEST12.	BEST32.	LAESVI in ml/sq.m
9	p1f9q003	Num	8	BEST12.	BEST32.	3. RA Volume
10	p1f9q004a	Num	8	BEST12.	BEST32.	RAESVI in ml/sq.m
11	p1f9q005	Num	8	BEST12.	BEST32.	4. LV Mass
12	p1f9q006	Num	8	BEST12.	BEST32.	5. LV Volume
13	p1f9q006a	Num	8	BEST12.	BEST32.	LV end systolic dimension LVESD
14	p1f9q006b	Num	8	BEST12.	BEST32.	LV end systolic volume LVESV
15	p1f9q006c	Num	8	BEST12.	BEST32.	LV end diastolic dimension LVEDD
16	p1f9q006d	Num	8	BEST12.	BEST32.	LV end diastolic volume LVEDV
17	p1f9q006e	Num	8	BEST12.	BEST32.	LV posterior wall thickness at end-diastole LVPwD (in mm)
18	p1f9q006e_2	Num	8	BEST12.	BEST32.	OR LVPwD (in cm)
19	p1f9q007	Num	8	BEST12.	BEST32.	6. LV Ejection Fraction
20	p1f9q008	Num	8	BEST12.	BEST32.	7. Fractional Shortening (PEDIATRICS ONLY)
21	p1f9q009a	Num	8	BEST12.	BEST32.	Apical chamber average
22	p1f9q00a_dys	Num	8	BEST12.	BEST32.	a) Date of most recent ECHO
23	p1f9q00__1	Num	8	BEST12.	BEST32.	Most recent ECHO (choice=ECHO report not available)
24	p1f9q00c	Num	8	BEST12.	BEST32.	c) Patient's Body Mass Index (BMI)
25	p1f9q00d	Num	8	BEST12.	BEST32.	d) Heart rate on date of ECHO
26	p1f9q00f	Num	8	BEST12.	BEST32.	e) Pericardial effusion
27	p1f9q010	Num	8	BEST12.	BEST32.	9. Septal e' Velocity
28	p1f9q012	Num	8	BEST12.	BEST32.	10. Lateral e' Velocity
29	p1f9q014	Num	8	BEST12.	BEST32.	11. E/A Ratio
30	p1f9q015	Num	8	BEST12.	BEST32.	12. RV Size
31	p1f9q015a	Num	8	BEST12.	BEST32.	RV basal diameter
32	p1f9q015c	Num	8	BEST12.	BEST32.	RV end diastolic dimension RVIDd
33	p1f9q017	Num	8	BEST12.	BEST32.	13. RV Systolic Pressure, Estimated
34	p1f9q018	Num	8	BEST12.	BEST32.	14. RV Systolic Excursion Velocity
35	p1f9q019	Num	8	BEST12.	BEST32.	15. RV Hypertrophy
36	p1f9q020	Num	8	BEST12.	BEST32.	16. RV Function
37	p1f9q021	Num	8	BEST12.	BEST32.	17. Interventricular Septum Diameter IVSD in (in mm)

Num	Variable	Type	Len	Format	Informat	Label
38	p1f9q029	Char	1	\$1.	\$1.	17. IVSD (in cm)
39	p1f9q021a	Num	8	BEST12.	BEST32.	Mention of interventricular septal flattening?
40	p1f9q022	Num	8	BEST12.	BEST32.	18. Aortic Valve Regurgitation
41	p1f9q023	Num	8	BEST12.	BEST32.	19. AV Peak Velocity
42	p1f9q024	Num	8	BEST12.	BEST32.	20. Left Ventricular Outflow Tract (LVOT) Peak Velocity
43	p1f9q025	Num	8	BEST12.	BEST32.	21. LVOT Velocity Time Integral
44	p1f9q026	Num	8	BEST12.	BEST32.	22. AV Mean Gradient
45	p1f9q027	Num	8	BEST12.	BEST32.	23. LVOT Diameter
46	p1f9q028	Num	8	BEST12.	BEST32.	24. Mitral Valve Regurgitation
47	p1f9q030	Num	8	BEST12.	BEST32.	25. E wave Mitral Inflow Velocity
48	p1f9q031	Num	8	BEST12.	BEST32.	26. A wave Mitral Inflow Velocity
49	p1f9q033	Num	8	BEST12.	BEST32.	27. Tricuspid Valve Regurgitation
50	p1f9q034	Num	8	BEST12.	BEST32.	28. TR Peak (Jet) Velocity
51	p1f9q035	Num	8	BEST12.	BEST32.	29. Tricuspid Annular Plane Systolic Excursion (TAPSE) TAPSE (in mm)
52	p1f9q052	Char	1	\$1.	\$1.	29. TAPSE (in cm)
53	p1f9q036	Num	8	BEST12.	BEST32.	30. Pulmonic Valve Regurgitation
54	p1f9q037	Num	8	BEST12.	BEST32.	31. IVC Diameter
55	p1f9q038	Num	8	BEST12.	BEST32.	32. Arrhythmia
56	p1f9q039	Num	8	BEST12.	BEST32.	33. Ventricular rate
57	p1f9q039b__1	Num	8	BEST12.	BEST32.	33. Ventricular rate (choice=NA)
58	p1f9q040	Num	8	BEST12.	BEST32.	34. PR Interval
59	p1f9q040b__1	Num	8	BEST12.	BEST32.	34. PR Interval (choice=NA)
60	p1f9q041	Num	8	BEST12.	BEST32.	35. QRS duration
61	p1f9q041b__1	Num	8	BEST12.	BEST32.	35. QRS duration (choice=NA)
62	p1f9q042_qt	Num	8	BEST12.	BEST32.	36. QT/QTc
63	p1f9q042_qtc	Num	8	BEST12.	BEST32.	36. QT/QTc
64	p1f9q042b__1	Num	8	BEST12.	BEST32.	36. QT/QTc (choice=NA)
65	p1f9q043b__1	Num	8	BEST12.	BEST32.	37. P-R-T axis (choice=NA)
66	p1f9q043p	Num	8	BEST12.	BEST32.	37. P-R-T axis, P:
67	p1f9q043r	Num	8	BEST12.	BEST32.	37. P-R-T axis, R:
68	p1f9q043t	Num	8	BEST12.	BEST32.	37. P-R-T axis, T:
69	p1f9q044	Num	8	BEST12.	BEST32.	38. RA pressure (mean)
70	p1f9q044b__1	Num	8	BEST12.	BEST32.	38. RA pressure (mean) (choice=NA)
71	p1f9q045	Num	8	BEST12.	BEST32.	39. RV pressure (mean)
72	p1f9q045b__1	Num	8	BEST12.	BEST32.	39. RV pressure (mean) (choice=NA)
73	p1f9q046	Num	8	BEST12.	BEST32.	40. PA pressure (mean)
74	p1f9q046b__1	Num	8	BEST12.	BEST32.	40. PA pressure (mean) (choice=NA)
75	p1f9q047	Num	8	BEST12.	BEST32.	41. Pulmonary artery saturation
76	p1f9q047b__1	Num	8	BEST12.	BEST32.	41. Pulmonary artery saturation (choice=NA)

Num	Variable	Type	Len	Format	Informat	Label
77	p1f9q048	Num	8	BEST12.	BEST32.	42. Pulmonary vascular resistance
78	p1f9q048b___1	Num	8	BEST12.	BEST32.	42. Pulmonary vascular resistance (choice=NA)
79	p1f9q049	Num	8	BEST12.	BEST32.	43. Pulmonary capillary wedge pressure (PCWP or PAWP)
80	p1f9q049b___1	Num	8	BEST12.	BEST32.	43. Pulmonary capillary wedge pressure (PCWP or PAWP) (choice=NA)
81	p1f9q050	Num	8	BEST12.	BEST32.	44. Cardiac output
82	p1f9q050b_2___1	Num	8	BEST12.	BEST32.	45. Cardiac index (choice=NA)
83	p1f9q050b___1	Num	8	BEST12.	BEST32.	44. Cardiac output (choice=NA)
84	p1f9q051	Num	8	BEST12.	BEST32.	45. Cardiac index
85	p1f9qb0a_dys	Num	8	BEST12.	BEST32.	a) Date of most recent EKG
86	p1f9qb0___1	Num	8	BEST12.	BEST32.	Most recent EKG (choice=EKG not available)

Data Set Name: *scdicii_healthcareutilization.sas7bdat*

Num	Variable	Type	Len	Format	Informat	Label
1	newid	Char	8	\$8.	\$8.	Subject ID
2	site	Num	8	BEST12.	BEST32.	Site
3	p1f11q00dys	Num	8	BEST12.	BEST32.	Date Form Completed
4	p1f11q01	Num	8	BEST12.	BEST32.	Has the person visited the following providers or facilities in the 12 months prior to consenting to participate in SCDIC-II? Primary care physician
5	p1f11q02	Num	8	BEST12.	BEST32.	Has the person visited the following providers or facilities in the 12 months prior to consenting to participate in SCDIC-II? Hematologist
6	p1f11q03	Num	8	BEST12.	BEST32.	Has the person visited the following providers or facilities in the 12 months prior to consenting to participate in SCDIC-II? Nephrologist
7	p1f11q04	Num	8	BEST12.	BEST32.	Has the person visited the following providers or facilities in the 12 months prior to consenting to participate in SCDIC-II? Cardiologist
8	p1f11q05	Num	8	BEST12.	BEST32.	Has the person visited the following providers or facilities in the 12 months prior to consenting to participate in SCDIC-II? Pulmonologist
9	p1f11q06	Num	8	BEST12.	BEST32.	Has the person visited the following providers or facilities in the 12 months prior to consenting to participate in SCDIC-II? Behavioral medicine/psychiatrist
10	p1f11q07	Num	8	BEST12.	BEST32.	Has the person visited the following providers or facilities in the 12 months prior to consenting to participate in SCDIC-II? Orthopedic surgeon
11	p1f11q08	Num	8	BEST12.	BEST32.	Has the person visited the following providers or facilities in the 12 months prior to consenting to participate in SCDIC-II? Ophthalmologist
12	p1f11q09	Num	8	BEST12.	BEST32.	Has the person visited the following providers or facilities in the 12 months prior to consenting to participate in SCDIC-II? Neurologist
13	p1f11q10	Num	8	BEST12.	BEST32.	Has the person visited the following providers or facilities in the 12 months prior to consenting to participate in SCDIC-II? OB/GYN-pregnancy related
14	p1f11q11	Num	8	BEST12.	BEST32.	Has the person visited the following providers or facilities in the 12 months prior to consenting to participate in SCDIC-II? OB/GYN-all other reasons
15	p1f11q12	Num	8	BEST12.	BEST32.	Has the person visited the following providers or facilities in the 12 months prior to consenting to participate in SCDIC-II? Pain center
16	p1f11q12a	Num	8	BEST12.	BEST32.	Pain center: How many visits?
17	p1f11q13	Num	8	BEST12.	BEST32.	Has the person visited the following providers or facilities in the 12 months prior to consenting to participate in SCDIC-II? ED/EDTR
18	p1f11q13a	Num	8	BEST12.	BEST32.	ED/EDTR: How many visits?
19	p1f11q14	Num	8	BEST12.	BEST32.	Has the person visited the following providers or facilities in the 12 months prior to consenting to participate in SCDIC-II? Hospital admission
20	p1f11q14a	Num	8	BEST12.	BEST32.	Hospital admission: How many admissions?
21	p1f11q15	Num	8	BEST12.	BEST32.	Has the person visited the following providers or facilities in the 12 months prior to consenting to participate in SCDIC-II? Transfusions - simple
22	p1f11q15a	Num	8	BEST12.	BEST32.	Transfusions - simple: How many?
23	p1f11q16	Num	8	BEST12.	BEST32.	Has the person visited the following providers or facilities in the 12 months prior to consenting to participate in SCDIC-II? Transfusions - exchange
24	p1f11q16a	Num	8	BEST12.	BEST32.	Transfusions - exchange: How many?

Data Set Name: scdicii_labform_yr1.sas7bdat

Num	Variable	Type	Len	Format	Informat	Label
1	newid	Char	8	\$8.	\$8.	Subject ID
2	site	Num	8	BEST12.	BEST32.	Site
3	p3f2q00_dys	Num	8	BEST12.	BEST32.	Form completion date
4	p3f2q0__1	Num	8	BEST12.	BEST32.	Form complete, Laboratory records not available
5	p3f2q1_1	Num	8	BEST12.	BEST32.	1. Nucleated RBC Test results
6	p3f2q1_1b	Num	8	BEST12.	BEST32.	1. Nucleated RBC Unit
7	p3f2q1_2dys	Num	8	BEST12.	BEST32.	1. Nucleated RBC Date of Most Recent
8	p3f2q1__1	Num	8	BEST12.	BEST32.	1. Nucleated RBC (choice=NA)
9	p3f2q2_1	Num	8	BEST12.	BEST32.	2. White Blood Cells Test results
10	p3f2q2_2dys	Num	8	BEST12.	BEST32.	2. White Blood Cells Date of Most Recent
11	p3f2q2__1	Num	8	BEST12.	BEST32.	2. White Blood Cells (choice=NA)
12	p3f2q3_1	Num	8	BEST12.	BEST32.	3. RBC Test results
13	p3f2q3_2dys	Num	8	BEST12.	BEST32.	3. RBC Date of Most Recent
14	p3f2q3__1	Num	8	BEST12.	BEST32.	3. RBC (choice=NA)
15	p3f2q4_1	Num	8	BEST12.	BEST32.	4. Hemoglobin Test results
16	p3f2q4_2dys	Num	8	BEST12.	BEST32.	4. Hemoglobin Date of Most Recent
17	p3f2q4__1	Num	8	BEST12.	BEST32.	4. Hemoglobin (choice=NA)
18	p3f2q5_1	Num	8	BEST12.	BEST32.	5. Hematocrit Test results
19	p3f2q5_2dys	Num	8	BEST12.	BEST32.	5. Hematocrit Date of Most Recent
20	p3f2q5__1	Num	8	BEST12.	BEST32.	5. Hematocrit (choice=NA)
21	p3f2q6_1	Num	8	BEST12.	BEST32.	6. MCV Test results
22	p3f2q6_2dys	Num	8	BEST12.	BEST32.	6. MCV Date of Most Recent
23	p3f2q6__1	Num	8	BEST12.	BEST32.	6. MCV (choice=NA)
24	p3f2q7_1	Num	8	BEST12.	BEST32.	7. MCH Test results
25	p3f2q7_2dys	Num	8	BEST12.	BEST32.	7. MCH Date of Most Recent
26	p3f2q7__1	Num	8	BEST12.	BEST32.	7. MCH (choice=NA)
27	p3f2q8_1	Num	8	BEST12.	BEST32.	8. MCHC Test results
28	p3f2q8_2dys	Num	8	BEST12.	BEST32.	8. MCHC Date of Most Recent
29	p3f2q8__1	Num	8	BEST12.	BEST32.	8. MCHC (choice=NA)
30	p3f2q9_1	Num	8	BEST12.	BEST32.	9. Platelets Test results
31	p3f2q9_2dys	Num	8	BEST12.	BEST32.	9. Platelets Date of Most Recent
32	p3f2q9__1	Num	8	BEST12.	BEST32.	9. Platelets (choice=NA)
33	p3f2q10_1	Num	8	BEST12.	BEST32.	10. Neutrophils Test results
34	p3f2q10__1	Num	8	BEST12.	BEST32.	10. Neutrophils (segmented and band together) (choice=NA)
35	p3f2q11_1	Num	8	BEST12.	BEST32.	11. Lymphocytes Test results
36	p3f2q11_2dys	Num	8	BEST12.	BEST32.	11. Lymphocytes Date of Most Recent

Num	Variable	Type	Len	Format	Informat	Label
37	p3f2q11___1	Num	8	BEST12.	BEST32.	11. Lymphocytes (choice=NA)
38	p3f2q12_1	Num	8	BEST12.	BEST32.	12. Monocytes Test results
39	p3f2q12_2dys	Num	8	BEST12.	BEST32.	12. Monocytes Date of Most Recent
40	p3f2q12___1	Num	8	BEST12.	BEST32.	12. Monocytes (choice=NA)
41	p3f2q13_1	Num	8	BEST12.	BEST32.	14. Reticulocytes Test results %
42	p3f2q13_4	Num	8	BEST12.	BEST32.	14. Reticulocytes Test results
43	p3f2q13_3dys	Num	8	BEST12.	BEST32.	14. Reticulocytes Date of Most Recent
44	p3f2q13_4b	Num	8	BEST12.	BEST32.	14. Reticulocytes Unit
45	p3f2q13___1	Num	8	BEST12.	BEST32.	14. Reticulocytes (choice=NA)
46	p3f2q14_1	Num	8	BEST12.	BEST32.	15. Serum BUN Test results
47	p3f2q14_2dys	Num	8	BEST12.	BEST32.	15. Serum BUN Date of Most Recent
48	p3f2q14___1	Num	8	BEST12.	BEST32.	15. Serum BUN (choice=NA)
49	p3f2q15_1	Num	8	BEST12.	BEST32.	16. Serum Creatinine Test results
50	p3f2q15_2dys	Num	8	BEST12.	BEST32.	16. Serum Creatinine Date of Most Recent
51	p3f2q15___1	Num	8	BEST12.	BEST32.	16. Serum Creatinine (choice=NA)
52	p3f2q16_1	Num	8	BEST12.	BEST32.	13. Eosinophils Test results
53	p3f2q16_2dys	Num	8	BEST12.	BEST32.	13. Eosinophils Date of Most Recent
54	p3f2q16___1	Num	8	BEST12.	BEST32.	13. Eosinophils (choice=NA)
55	p3f2q17_1	Num	8	BEST12.	BEST32.	17. Estimated creatinine clearance Test results
56	p3f2q17_2dys	Num	8	BEST12.	BEST32.	17. Estimated creatinine clearance Date of Most Recent
57	p3f2q17___1	Num	8	BEST12.	BEST32.	17. Estimated creatinine clearance (choice=NA)
58	p3f2q18_1	Num	8	BEST12.	BEST32.	18. Total Cholesterol Test results
59	p3f2q18_2dys	Num	8	BEST12.	BEST32.	18. Total Cholesterol Date of Most Recent
60	p3f2q18___1	Num	8	BEST12.	BEST32.	18. Total Cholesterol (choice=NA)
61	p3f2q19_1	Num	8	BEST12.	BEST32.	19. Non-Fasting HDL Test results
62	p3f2q19_2dys	Num	8	BEST12.	BEST32.	19. Non-Fasting HDL Date of Most Recent
63	p3f2q19___1	Num	8	BEST12.	BEST32.	19. Non-Fasting HDL (choice=NA)
64	p3f2q20_1	Num	8	BEST12.	BEST32.	20. Fasting HDL Test results
65	p3f2q20_2dys	Num	8	BEST12.	BEST32.	20. Fasting HDL Date of Most Recent
66	p3f2q20___1	Num	8	BEST12.	BEST32.	20. Fasting HDL (choice=NA)
67	p3f2q21_1	Num	8	BEST12.	BEST32.	21. Non-Fasting LDL Test results
68	p3f2q21_2dys	Num	8	BEST12.	BEST32.	21. Non-Fasting LDL Date of Most Recent
69	p3f2q21___1	Num	8	BEST12.	BEST32.	21. Non-Fasting LDL (choice=NA)
70	p3f2q22_1	Num	8	BEST12.	BEST32.	22. Fasting LDL Test results
71	p3f2q22_2dys	Num	8	BEST12.	BEST32.	22. Fasting LDL Date of Most Recent
72	p3f2q22___1	Num	8	BEST12.	BEST32.	22. Fasting LDL (choice=NA)
73	p3f2q23_1	Num	8	BEST12.	BEST32.	23. Triglyceride Test results
74	p3f2q23_2dys	Num	8	BEST12.	BEST32.	23. Triglyceride Date of Most Recent
75	p3f2q23___1	Num	8	BEST12.	BEST32.	23. Triglyceride (choice=NA)

Num	Variable	Type	Len	Format	Informat	Label
76	p3f2q24_1	Num	8	BEST12.	BEST32.	24. Non-Fasting Blood Glucose Test results
77	p3f2q24_2dys	Num	8	BEST12.	BEST32.	24. Non-Fasting Blood Glucose Date of Most Recent
78	p3f2q24___1	Num	8	BEST12.	BEST32.	24. Non-Fasting Blood Glucose (choice=NA)
79	p3f2q25_1	Num	8	BEST12.	BEST32.	25. Fasting Blood Glucose Test results
80	p3f2q25_2dys	Num	8	BEST12.	BEST32.	25. Fasting Blood Glucose Date of Most Recent
81	p3f2q25___1	Num	8	BEST12.	BEST32.	25. Fasting Blood Glucose (choice=NA)
82	p3f2q26_1	Num	8	BEST12.	BEST32.	26. CRP Test results
83	p3f2q26_1a	Num	8	BEST12.	BEST32.	26. CRP Unit
84	p3f2q26_2dys	Num	8	BEST12.	BEST32.	26. CRP Date of Most Recent
85	p3f2q26___1	Num	8	BEST12.	BEST32.	26. CRP (choice=NA)
86	p3f2q27_1	Num	8	BEST12.	BEST32.	27. Bilirubin serum, total Test results
87	p3f2q27_2dys	Num	8	BEST12.	BEST32.	27. Bilirubin serum, total Date of Most Recent
88	p3f2q27___1	Num	8	BEST12.	BEST32.	27. Bilirubin serum, total (choice=NA)
89	p3f2q28_1	Num	8	BEST12.	BEST32.	28. Bilirubin, serum, direct Test results
90	p3f2q28_2dys	Num	8	BEST12.	BEST32.	28. Bilirubin, serum, direct Date of Most Recent
91	p3f2q28___1	Num	8	BEST12.	BEST32.	28. Bilirubin, serum, direct (choice=NA)
92	p3f2q29_1	Num	8	BEST12.	BEST32.	29. AST Test results
93	p3f2q29_2dys	Num	8	BEST12.	BEST32.	29. AST Date of Most Recent
94	p3f2q29___1	Num	8	BEST12.	BEST32.	29. AST (choice=NA)
95	p3f2q30_1	Num	8	BEST12.	BEST32.	30. ALT Test results
96	p3f2q30_2dys	Num	8	BEST12.	BEST32.	30. ALT Date of Most Recent
97	p3f2q30___1	Num	8	BEST12.	BEST32.	30. ALT (choice=NA)
98	p3f2q31_1	Num	8	BEST12.	BEST32.	31. Alkaline Phosphatase Test results
99	p3f2q31_2dys	Num	8	BEST12.	BEST32.	31. Alkaline Phosphatase Date of Most Recent
100	p3f2q31___1	Num	8	BEST12.	BEST32.	31. Alkaline Phosphatase (choice=NA)
101	p3f2q32_1	Num	8	BEST12.	BEST32.	32. Total Protein (plasma) Test results
102	p3f2q32_2dys	Num	8	BEST12.	BEST32.	32. Total Protein (plasma) Date of Most Recent
103	p3f2q32___1	Num	8	BEST12.	BEST32.	32. Total Protein (plasma) (choice=NA)
104	p3f2q33_1	Num	8	BEST12.	BEST32.	33. Albumin Test results
105	p3f2q33_2dys	Num	8	BEST12.	BEST32.	33. Albumin Date of Most Recent
106	p3f2q33___1	Num	8	BEST12.	BEST32.	33. Albumin (choice=NA)
107	p3f2q34_1	Num	8	BEST12.	BEST32.	34. LDH (serum) Test results
108	p3f2q34_2dys	Num	8	BEST12.	BEST32.	34. LDH (serum) Date of Most Recent
109	p3f2q34_3a	Num	8	BEST12.	BEST32.	34. LDH (serum) minimum reference range
110	p3f2q34_3b	Num	8	BEST12.	BEST32.	34. LDH (serum) max reference range
111	p3f2q34___1	Num	8	BEST12.	BEST32.	34. LDH (serum) (choice=NA)
112	p3f2q35_1	Num	8	BEST12.	BEST32.	37. NT-pro-BNP Test results
113	p3f2q35_2dys	Num	8	BEST12.	BEST32.	37. NT-pro-BNP Date of Most Recent
114	p3f2q35___1	Num	8	BEST12.	BEST32.	37. NT-pro-BNP (choice=NA)

Num	Variable	Type	Len	Format	Informat	Label
115	p3f2q36_1	Num	8	BEST12.	BEST32.	38. BNP Test results
116	p3f2q36_2dys	Num	8	BEST12.	BEST32.	38. BNP Date of Most Recent
117	p3f2q36___1	Num	8	BEST12.	BEST32.	38. BNP (choice=NA)
118	p3f2q37_1	Num	8	BEST12.	BEST32.	39. Serum iron Test results ug/dL
119	p3f2q37_3	Char	1	\$1.	\$1.	39. Serum iron Test results mcg/dL
120	p3f2q37_2dys	Num	8	BEST12.	BEST32.	39. Serum iron Date of Most Recent
121	p3f2q37___1	Num	8	BEST12.	BEST32.	39. Serum iron (choice=NA)
122	p3f2q38_1	Num	8	BEST12.	BEST32.	40. TIBC Test results ug/dL
123	p3f2q38_3	Char	1	\$1.	\$1.	40. TIBC Test results mcg/dL
124	p3f2q38_2dys	Num	8	BEST12.	BEST32.	40. TIBC Date of Most Recent
125	p3f2q38___1	Num	8	BEST12.	BEST32.	40. Total iron binding capacity (TIBC) (choice=NA)
126	p3f2q39_1a	Num	8	BEST12.	BEST32.	41. Serum transferrin Unit
127	p3f2q39_2dys	Num	8	BEST12.	BEST32.	41. Serum transferrin Date of Most Recent
128	p3f2q39___1	Num	8	BEST12.	BEST32.	41. Serum transferrin (choice=NA)
129	p3f2q40_1	Num	8	BEST12.	BEST32.	42. Ferritin Test results
130	p3f2q40_2dys	Num	8	BEST12.	BEST32.	42. Ferritin Date of Most Recent
131	p3f2q40___1	Num	8	BEST12.	BEST32.	42. Ferritin (choice=NA)
132	p3f2q41_1	Num	8	BEST12.	BEST32.	43. 25-Hydroxy Vitamin D Test results
133	p3f2q41_2dys	Num	8	BEST12.	BEST32.	43. 25-Hydroxy Vitamin D Date of Most Recent
134	p3f2q41___1	Num	8	BEST12.	BEST32.	43. 25-Hydroxy Vitamin D (choice=NA)
135	p3f2q42_1	Num	8	BEST12.	BEST32.	44. EPOTest results mU/ml
136	p3f2q42_3	Char	1	\$1.	\$1.	44. EPOTest results miu/ml
137	p3f2q42_2dys	Num	8	BEST12.	BEST32.	44. EPO Date of Most Recent
138	p3f2q42___1	Num	8	BEST12.	BEST32.	44. Erythropoietin (EPO) (choice=NA)
139	p3f2q43_1	Num	8	BEST12.	BEST32.	45. Urine albumin or Urine microalbumin Test results
140	p3f2q43_1a	Num	8	BEST12.	BEST32.	45. Urine albumin or Urine microalbumin Unit
141	p3f2q43_2dys	Num	8	BEST12.	BEST32.	45. Urine albumin or Urine microalbumin Date of Most Recent
142	p3f2q43___1	Num	8	BEST12.	BEST32.	45. Urine albumin or Urine microalbumin (choice=NA)
143	p3f2q44_1	Num	8	BEST12.	BEST32.	46. Urine albumin / creatinine Test results mcg/mg
144	p3f2q44_3	Char	1	\$1.	\$1.	46. Urine albumin / creatinine Test results mg/dL
145	p3f2q44_2dys	Num	8	BEST12.	BEST32.	46. Urine albumin / creatinine Date of Most Recent
146	p3f2q44___1	Num	8	BEST12.	BEST32.	46. Urine albumin / creatinine (choice=NA)
147	p3f2q45_1	Num	8	BEST12.	BEST32.	47. Urine protein Test results
148	p3f2q45_2dys	Num	8	BEST12.	BEST32.	47. Urine protein Date of Most Recent
149	p3f2q45___1	Num	8	BEST12.	BEST32.	47. Urine protein (dipstick) (choice=NA)
150	p3f2q46_1	Num	8	BEST12.	BEST32.	48. Urine protein / creatinine Test results
151	p3f2q46_2dys	Num	8	BEST12.	BEST32.	48. Urine protein / creatinine Date of Most Recent
152	p3f2q46___1	Num	8	BEST12.	BEST32.	48. Urine protein / creatinine (choice=NA)
153	p3f2q47_1	Num	8	BEST12.	BEST32.	49. Urine dipstick heme Test results

Num	Variable	Type	Len	Format	Informat	Label
154	p3f2q47_2dys	Num	8	BEST12.	BEST32.	49. Urine dipstick heme Date of Most Recent
155	p3f2q47___1	Num	8	BEST12.	BEST32.	49. Urine dipstick heme (choice=NA)
156	p3f2q48_1r	Num	8	BEST12.	BEST32.	50. Urine microscopic RBCs Test results
157	p3f2q48_1r_2___1	Num	8	BEST12.	BEST32.	50. Urine microscopic RBCs if < 100, enter exact value OR (choice=>= 100 10^3/mm^3)
158	p3f2q48_2dys	Num	8	BEST12.	BEST32.	50. Urine microscopic RBCs Date of Most Recent
159	p3f2q48___1	Num	8	BEST12.	BEST32.	50. Urine microscopic RBCs (choice=NA)
160	p3f2q48_unit	Num	8	BEST12.	BEST32.	50. Urine microscopic RBCs Unit
161	p3f2q49_1r	Num	8	BEST12.	BEST32.	51. Urine microscopic WBCs Test results
162	p3f2q49_1r_2___1	Num	8	BEST12.	BEST32.	51. Urine microscopic WBCs if < 100, enter exact value OR (choice=>= 100 10^3/mm^3)
163	p3f2q49_2dys	Num	8	BEST12.	BEST32.	51. Urine microscopic WBCs Date of Most Recent
164	p3f2q49___1	Num	8	BEST12.	BEST32.	51. Urine microscopic WBCs (choice=NA)
165	p3f2q49_unit	Num	8	BEST12.	BEST32.	51. Urine microscopic WBCs Unit
166	p3f2q50_2dys	Num	8	BEST12.	BEST32.	Date of Most Recent CBC
167	p3f2q50___1	Num	8	BEST12.	BEST32.	CBC (choice=NA)
168	p3f2q51_1	Num	8	BEST12.	BEST32.	52. Hb A
169	p3f2q51_2	Num	8	BEST12.	BEST32.	52. Hb A2
170	p3f2q51_3	Num	8	BEST12.	BEST32.	52. Hb C
171	p3f2q51_4	Num	8	BEST12.	BEST32.	52. Hb D
172	p3f2q51_5	Num	8	BEST12.	BEST32.	52. Hb E
173	p3f2q51_6	Num	8	BEST12.	BEST32.	52. Hb F
174	p3f2q51_7	Num	8	BEST12.	BEST32.	52. Hb O
175	p3f2q51_8	Num	8	BEST12.	BEST32.	52. Hb S
176	p3f2q51_10	Num	8	BEST12.	BEST32.	52. Other
177	p3f2q51_12	Num	8	BEST12.	BEST32.	52. Genetic modified A variant
178	p3f2q51_11dys	Num	8	BEST12.	BEST32.	52. Hemoglobin fractionation Date of Most Recent
179	p3f2q51___1	Num	8	BEST12.	BEST32.	52. Hemoglobin fractionation, most recent (choice=NA)
180	p3f2q52_2dys	Num	8	BEST12.	BEST32.	Metabolic Panel Date of Most Recent
181	p3f2q52___1	Num	8	BEST12.	BEST32.	Metabolic Panel (choice=NA)
182	p3f2q53_1	Num	8	BEST12.	BEST32.	35. Direct antiglobulin test-Anti-IgG Test results
183	p3f2q53_2dys	Num	8	BEST12.	BEST32.	35. Direct antiglobulin test-Anti-IgG Date of Most Recent
184	p3f2q53___1	Num	8	BEST12.	BEST32.	35. Direct antiglobulin test-Anti-IgG* (choice=NA)
185	p3f2q54_1	Num	8	BEST12.	BEST32.	6. Direct antiglobulin test-Anti-C3d Test results
186	p3f2q54_2dys	Num	8	BEST12.	BEST32.	6. Direct antiglobulin test-Anti-C3d Date of Most Recent
187	p3f2q54___1	Num	8	BEST12.	BEST32.	36. Direct antiglobulin test-Anti-C3d* (choice=NA)
188	p3f2q55_2dys	Num	8	BEST12.	BEST32.	Lipid Panel Date of Most Recent
189	p3f2q55___1	Num	8	BEST12.	BEST32.	Lipid Panel (choice=NA)

Data Set Name: scdicii_mra_yr1enrol.sas7bdat

Num	Variable	Type	Len	Format	Informat	Label
1	newid	Char	8	\$8.	\$8.	Subject ID
2	site	Num	8	BEST12.	BEST32.	Site
3	p3f4q00adys	Num	8	BEST12.	BEST32.	Date this form completed
4	p3f4q03	Num	8	BEST12.	BEST32.	Confirmed enrollment diagnosis: Diagnosis must be supported by source documentation.
5	p3f4q03a	Num	8	BEST12.	BEST32.	What was the basis for diagnosis?
6	p3f4q04	Num	8	BEST12.	BEST32.	Approximate age of first diagnosis (physician confirmed)
7	p3f4q04a	Num	8	BEST12.	BEST32.	Age in years
8	p3f4q04b___1	Num	8	BEST12.	BEST32.	Medical records not available, form complete
9	p3f4q05	Num	8	BEST12.	BEST32.	Most recent test results for alpha-thalassemia?
10	p3f4q06_1	Num	8	BEST12.	BEST32.	4. Height (CM):Measurements
11	p3f4q06_2dys	Num	8	BEST12.	BEST32.	4. Height: date
12	p3f4q06_3	Num	8	BEST12.	BEST32.	4. Height: Steady state?
13	p3f4q06___1	Num	8	BEST12.	BEST32.	4. Height (CM): Not in record
14	p3f4q07_1	Num	8	BEST12.	BEST32.	5. Weight(KG): Measurements
15	p3f4q07_2dys	Num	8	BEST12.	BEST32.	5. Weight: date
16	p3f4q07_3	Num	8	BEST12.	BEST32.	5. Weight: Steady state?
17	p3f4q07___1	Num	8	BEST12.	BEST32.	5. Weight(KG): Not in record
18	p3f4q08_1	Num	8	BEST12.	BEST32.	6. Temperature (Celsius):Measurements
19	p3f4q08_2dys	Num	8	BEST12.	BEST32.	6. Temperature: date
20	p3f4q08_3	Num	8	BEST12.	BEST32.	6. Temperature: Steady state?
21	p3f4q08___1	Num	8	BEST12.	BEST32.	6. Temperature (Celsius): Not in record
22	p3f4q09_1	Num	8	BEST12.	BEST32.	7. Heart Rate (Beats/Minute):Measurements
23	p3f4q09_2dys	Num	8	BEST12.	BEST32.	7. Heart Rate: date
24	p3f4q09_3	Num	8	BEST12.	BEST32.	7. Heart Rate: Steady state?
25	p3f4q09___1	Num	8	BEST12.	BEST32.	7. Heart Rate (Beats/Minute): Not in record
26	p3f4q100___1	Num	8	BEST12.	BEST32.	Liver cirrhosis -Currently receiving treatment
27	p3f4q101___1	Num	8	BEST12.	BEST32.	Intrahepatic cholelithiasis -Currently receiving treatment
28	p3f4q102___1	Num	8	BEST12.	BEST32.	Hepatitis B -Currently receiving treatment
29	p3f4q103___1	Num	8	BEST12.	BEST32.	Hepatitis C -Currently receiving treatment
30	p3f4q104___1	Num	8	BEST12.	BEST32.	Intrahepatic cholelithiasis -Currently receiving treatment
31	p3f4q105___1	Num	8	BEST12.	BEST32.	Hepatic sequestration -Currently receiving treatment
32	p3f4q106___1	Num	8	BEST12.	BEST32.	Bridging fibrosis -Currently receiving treatment
33	p3f4q10_1	Num	8	BEST12.	BEST32.	8. Respiration Rate (Breaths/Minute):Measurements
34	p3f4q10_2dys	Num	8	BEST12.	BEST32.	8. Respiration Rate: date
35	p3f4q10_3	Num	8	BEST12.	BEST32.	8. Respiration Rate :Steady state?
36	p3f4q10___1	Num	8	BEST12.	BEST32.	8. Respiration Rate (Breaths/Minute): Not in record

Num	Variable	Type	Len	Format	Informat	Label
37	p3f4q11_1	Num	8	BEST12.	BEST32.	9. Oxygen Saturation (SpO2):Measurements
38	p3f4q11_2dys	Num	8	BEST12.	BEST32.	9. Oxygen Saturation: date
39	p3f4q11_3	Num	8	BEST12.	BEST32.	9. Oxygen Saturation: Steady state?
40	p3f4q11___1	Num	8	BEST12.	BEST32.	9. Oxygen Saturation (SpO2): Not in record
41	p3f4q12_1	Num	8	BEST12.	BEST32.	Systolic
42	p3f4q12_2	Num	8	BEST12.	BEST32.	Diastolic
43	p3f4q12_3	Num	8	BEST12.	BEST32.	ON ANTI-HYPERTENSIVE MEDS?
44	p3f4q12_5dys	Num	8	BEST12.	BEST32.	10. Blood Pressure: date
45	p3f4q12_6	Num	8	BEST12.	BEST32.	10. Blood Pressure: Steady state?
46	p3f4q12___1	Num	8	BEST12.	BEST32.	10. Blood Pressure: Not in record
47	p3f4q12_b	Num	8	BEST12.	BEST32.	Has the subject ever used hydroxyurea?
48	p3f4q12b	Num	8	BEST12.	BEST32.	Has the subject ever taken Endari?
49	p3f4q12b_adys	Num	8	BEST12.	BEST32.	a. Endari Start date
50	p3f4q12b_b1___1	Num	8	BEST12.	BEST32.	b. Endari Stop/last date =Currently using
51	p3f4q12b_bdys	Num	8	BEST12.	BEST32.	b. Endari Stop/last date
52	p3f4q12b_c	Num	8	BEST12.	BEST32.	c. Endari Total duration of use
53	p3f4q12b_c1	Num	8	BEST12.	BEST32.	Endari Total duration of use Unit
54	p3f4q12b_c2	Num	8	BEST12.	BEST32.	Endari Current dose Unit
55	p3f4q12b_d	Num	8	BEST12.	BEST32.	d. Endari Current dose
56	p3f4q13	Num	8	BEST12.	BEST32.	Is the subject currently taking hydroxyurea?
57	p3f4q13adys	Num	8	BEST12.	BEST32.	a. Hydroxyurea start date
58	p3f4q13b2	Num	8	BEST12.	BEST32.	Has the subject ever taken Adakveo?
59	p3f4q13b2_adys	Num	8	BEST12.	BEST32.	b. Hydroxyurea Stop/last date
60	p3f4q13b2_b1___1	Num	8	BEST12.	BEST32.	b. Adakveo Stop/last date =Currently using
61	p3f4q13b2_bdys	Num	8	BEST12.	BEST32.	a. Adakveo Start date
62	p3f4q13b2_c	Num	8	BEST12.	BEST32.	c. Adakveo Total duration of use
63	p3f4q13b2_c1	Num	8	BEST12.	BEST32.	Adakveo Total duration of use Unit
64	p3f4q13b2_c2	Num	8	BEST12.	BEST32.	Adakveo Current dose Unit
65	p3f4q13b2_d	Num	8	BEST12.	BEST32.	d. Adakveo Current dose
66	p3f4q13b3	Char	1	\$1.	\$1.	16. Is the subject currently taking Adakveo?
67	p3f4q13b_1___1	Num	8	BEST12.	BEST32.	b. Hydroxyurea Stop/last date= Currently Using
68	p3f4q13bdys	Num	8	BEST12.	BEST32.	b. Adakveo Stop/last date
69	p3f4q13c1	Char	1	\$1.	\$1.	Hydroxyurea Total duration of use Unit
70	p3f4q13c_2	Char	1	\$1.	\$1.	c. Hydroxyurea Total duration of use
71	p3f4q13d	Char	1	\$1.	\$1.	d. Hydroxyurea Current dose
72	p3f4q13d_2	Char	1	\$1.	\$1.	Hydroxyurea Dose unit
73	p3f4q14_b	Char	1	\$1.	\$1.	14. Is the subject currently taking Endari?
74	p3f4q14b	Num	8	BEST12.	BEST32.	Has the subject ever taken Oxbryta?
75	p3f4q14b_2	Char	1	\$1.	\$1.	18. Is the subject currently taking Oxbryta?

Num	Variable	Type	Len	Format	Informat	Label
76	p3f4q14b_adys	Num	8	BEST12.	BEST32.	a. Oxbryta Start date
77	p3f4q14b_b1__1	Num	8	BEST12.	BEST32.	b. Oxbryta Stop/last date =Currently using
78	p3f4q14b_bdys	Num	8	BEST12.	BEST32.	b. OxbrytaStop/last date
79	p3f4q14b_c	Num	8	BEST12.	BEST32.	c. Oxbryta Total duration of use
80	p3f4q14b_c1	Num	8	BEST12.	BEST32.	Oxbryta Total duration of use Unit
81	p3f4q14b_c2	Num	8	BEST12.	BEST32.	Oxbryta Current dose Unit
82	p3f4q14b_d	Num	8	BEST12.	BEST32.	d. Oxbryta Current dose
83	p3f4q32	Num	8	BEST12.	BEST32.	Avascular necrosis (check all that apply)
84	p3f4q32_2a	Num	8	BEST12.	BEST32.	Avascular necrosis - age most recent dx
85	p3f4q32_2dys	Num	8	BEST12.	BEST32.	Avascular necrosis - date most recent dx
86	p3f4q32a	Num	8	BEST12.	BEST32.	AVN hip
87	p3f4q32a_2dys	Num	8	BEST12.	BEST32.	AVN hip - date most recent dx
88	p3f4q32a_3__1	Num	8	BEST12.	BEST32.	AVN hip -Currently receiving treatment
89	p3f4q32a_4	Num	8	BEST12.	BEST32.	AVN hip - age most recent dx
90	p3f4q32b	Num	8	BEST12.	BEST32.	AVN shoulder
91	p3f4q32b_2dys	Num	8	BEST12.	BEST32.	AVN shoulder - date most recent dx
92	p3f4q32b_3__1	Num	8	BEST12.	BEST32.	AVN shoulder -Currently receiving treatment
93	p3f4q32b_4	Num	8	BEST12.	BEST32.	AVN shoulder - age most recent dx
94	p3f4q32c	Num	8	BEST12.	BEST32.	'AVN knee Ever present in timeframe
95	p3f4q32c_2dys	Num	8	BEST12.	BEST32.	AVN knee - date most recent dx
96	p3f4q32c_3__1	Num	8	BEST12.	BEST32.	AVN knee -Currently receiving treatment
97	p3f4q32c_4	Num	8	BEST12.	BEST32.	AVN knee - age most recent dx
98	p3f4q32d	Num	8	BEST12.	BEST32.	AVN other location
99	p3f4q32d_2__1	Num	8	BEST12.	BEST32.	AVN other location -Currently receiving treatment
100	p3f4q32d_3dys	Num	8	BEST12.	BEST32.	AVN other location - date most recent dx
101	p3f4q32d_4	Num	8	BEST12.	BEST32.	AVN other location - age most recent dx
102	p3f4q33__1	Num	8	BEST12.	BEST32.	Avascular necrosis -Currently receiving treatment
103	p3f4q35	Num	8	BEST12.	BEST32.	Chronic kidney disease
104	p3f4q35_2dys	Num	8	BEST12.	BEST32.	Chronic kidney disease - date most recent dx
105	p3f4q35_4	Num	8	BEST12.	BEST32.	Chronic kidney disease - age most recent dx
106	p3f4q36	Num	8	BEST12.	BEST32.	End stage renal disease
107	p3f4q36_2dys	Num	8	BEST12.	BEST32.	End stage most recent dx renal disease - date most recent dx
108	p3f4q36_4	Num	8	BEST12.	BEST32.	End stage renal disease - age most recent dx
109	p3f4q36a	Num	8	BEST12.	BEST32.	Kidney transplant
110	p3f4q36a_2dys	Char	1	\$1.	\$1.	Kidney transplant - date most recent dx
111	p3f4q36a_3	Num	8	BEST12.	BEST32.	Kidney transplant rejection
112	p3f4q36a_3b__1	Num	8	BEST12.	BEST32.	Kidney transplant -Currently receiving treatment
113	p3f4q36a_4	Char	1	\$1.	\$1.	Kidney transplant - age most recent dx
114	p3f4q37	Num	8	BEST12.	BEST32.	Priapism

Num	Variable	Type	Len	Format	Informat	Label
115	p3f4q37_2dys	Num	8	BEST12.	BEST32.	Priapism - date most recent dx
116	p3f4q37_4	Num	8	BEST12.	BEST32.	Priapism - age most recent dx
117	p3f4q38	Num	8	BEST12.	BEST32.	Stroke (check all that apply)
118	p3f4q38_2dys	Num	8	BEST12.	BEST32.	Stroke - date most recent dx
119	p3f4q38_4	Num	8	BEST12.	BEST32.	Stroke - age most recent dx
120	p3f4q38a	Num	8	BEST12.	BEST32.	Stroke ischemic
121	p3f4q38a_2dys	Num	8	BEST12.	BEST32.	Stroke ischemic - date most recent dx
122	p3f4q38a_3___1	Num	8	BEST12.	BEST32.	Stroke ischemic -Currently receiving treatment
123	p3f4q38a_4	Num	8	BEST12.	BEST32.	Stroke ischemic - age most recent dx
124	p3f4q38b	Num	8	BEST12.	BEST32.	Stroke hemorrhagic
125	p3f4q38b_2dys	Num	8	BEST12.	BEST32.	Stroke hemorrhagic - date most recent dx
126	p3f4q38b_3___1	Num	8	BEST12.	BEST32.	Stroke hemorrhagic -Currently receiving treatment
127	p3f4q38b_4	Char	1	\$1.	\$1.	Stroke hemorrhagic - age most recent dx
128	p3f4q38c	Num	8	BEST12.	BEST32.	Stroke Transient ischemic attack (TIA)
129	p3f4q38c_2dys	Num	8	BEST12.	BEST32.	Stroke Transient ischemic attack (TIA) - date most recent dx
130	p3f4q38c_3___1	Num	8	BEST12.	BEST32.	Stroke Transient ischemic attack (TIA) -Currently receiving treatment
131	p3f4q38c_4	Char	1	\$1.	\$1.	Stroke Transient ischemic attack (TIA) - age most recent dx
132	p3f4q38d	Num	8	BEST12.	BEST32.	Stroke ischemic (check all that apply)
133	p3f4q38d_2dys	Num	8	BEST12.	BEST32.	Stroke ischemic - date most recent dx
134	p3f4q38d_3___1	Num	8	BEST12.	BEST32.	Stroke ischemic -Currently receiving treatment
135	p3f4q38d_4	Num	8	BEST12.	BEST32.	'Stroke ischemic - age most recent dx
136	p3f4q39	Num	8	BEST12.	BEST32.	Intracranial bleeding
137	p3f4q39_2dys	Num	8	BEST12.	BEST32.	Intracranial bleeding - date most recent dx
138	p3f4q39_4	Num	8	BEST12.	BEST32.	Intracranial bleeding - age most recent dx
139	p3f4q40	Num	8	BEST12.	BEST32.	Pulmonary arterial hypertension
140	p3f4q40_2dys	Num	8	BEST12.	BEST32.	Pulmonary arterial hypertension - date most recent dx
141	p3f4q40_4	Num	8	BEST12.	BEST32.	Pulmonary arterial hypertension - age most recent dx
142	p3f4q40a	Num	8	BEST12.	BEST32.	a. Mean pulmonary artery pressure > or = to 25 mm Hg
143	p3f4q40a_2dys	Num	8	BEST12.	BEST32.	a. Mean pulmonary artery pressure > or = to 25 mm Hg - date most recent dx
144	p3f4q40a_3___1	Num	8	BEST12.	BEST32.	a. Mean pulmonary artery pressure > or = to 25 mm Hg -Currently receiving treatment
145	p3f4q40a_4	Num	8	BEST12.	BEST32.	a. Mean pulmonary artery pressure > or = to 25 mm Hg - age most recent dx
146	p3f4q40b	Num	8	BEST12.	BEST32.	b. Tricuspid regurgitation velocity (TRV) > or = to 3. 0 m/sec
147	p3f4q40b_2dys	Num	8	BEST12.	BEST32.	b. Tricuspid regurgitation velocity (TRV) > or = to 3. 0 m/sec - date most recent dx
148	p3f4q40b_3___1	Num	8	BEST12.	BEST32.	b. Tricuspid regurgitation velocity (TRV) > or = to 3. 0 m/sec -Currently receiving treatment
149	p3f4q40b_4	Num	8	BEST12.	BEST32.	b. Tricuspid regurgitation velocity (TRV) > or = to 3. 0 m/sec - age most recent dx

Num	Variable	Type	Len	Format	Informat	Label
150	p3f4q41	Num	8	BEST12.	BEST32.	Left ventricular dysfunction
151	p3f4q41_2dys	Num	8	BEST12.	BEST32.	Left ventricular dysfunction - date most recent dx
152	p3f4q41_4	Num	8	BEST12.	BEST32.	Left ventricular dysfunction - age most recent dx
153	p3f4q42	Num	8	BEST12.	BEST32.	Acute chest syndrome
154	p3f4q42_2dys	Num	8	BEST12.	BEST32.	Acute chest syndrome - date most recent dx
155	p3f4q42_4	Num	8	BEST12.	BEST32.	Acute chest syndrome - age most recent dx
156	p3f4q43	Num	8	BEST12.	BEST32.	Asthma
157	p3f4q43_2dys	Num	8	BEST12.	BEST32.	Asthma - date most recent dx
158	p3f4q43_4	Num	8	BEST12.	BEST32.	Asthma - age most recent dx
159	p3f4q44	Num	8	BEST12.	BEST32.	Gallstones/cholelithiasis, cholecystitis
160	p3f4q44_2dys	Num	8	BEST12.	BEST32.	Gallstones/cholelithiasis, cholecystitis - date most recent dx
161	p3f4q44_4	Num	8	BEST12.	BEST32.	Gallstones/cholelithiasis, cholecystitis - age most recent dx
162	p3f4q45	Num	8	BEST12.	BEST32.	Splenomegaly (check all that apply)
163	p3f4q45_2dys	Num	8	BEST12.	BEST32.	Splenomegaly - date most recent dx
164	p3f4q45_4_2	Num	8	BEST12.	BEST32.	Splenomegaly - age most recent dx
165	p3f4q45_4dys	Num	8	BEST12.	BEST32.	Splenic sequestration - date most recent dx
166	p3f4q45_5	Num	8	BEST12.	BEST32.	# sequestration episodes in past 12 months
167	p3f4q45a	Num	8	BEST12.	BEST32.	a. PRBC transfusion given for splenomegaly?
168	p3f4q45b	Num	8	BEST12.	BEST32.	b. Splenic sequestration
169	p3f4q45b_2dys	Num	8	BEST12.	BEST32.	Splenic infarcts - date most recent dx
170	p3f4q45b_3	Num	8	BEST12.	BEST32.	c. Splenic infarcts, symptomatic
171	p3f4q45b_3_4	Num	8	BEST12.	BEST32.	Splenic infarcts - age most recent dx
172	p3f4q45b_4__1	Num	8	BEST12.	BEST32.	Splenic sequestration -Currently receiving treatment
173	p3f4q45b_5__1	Num	8	BEST12.	BEST32.	Splenic infarcts -Currently receiving treatment
174	p3f4q45b_6	Num	8	BEST12.	BEST32.	Splenic sequestration - age most recent dx
175	p3f4q45c	Num	8	BEST12.	BEST32.	d. Hypersplenism
176	p3f4q45c_2dys	Num	8	BEST12.	BEST32.	Hypersplenism - date most recent dx
177	p3f4q45c_3__1	Num	8	BEST12.	BEST32.	Hypersplenism -Currently receiving treatment
178	p3f4q45c_4	Num	8	BEST12.	BEST32.	Hypersplenism - age most recent dx
179	p3f4q45d	Num	8	BEST12.	BEST32.	e. Splenectomy
180	p3f4q45d_2dys	Num	8	BEST12.	BEST32.	Splenectomy - date most recent dx
181	p3f4q45d_4	Num	8	BEST12.	BEST32.	Splenectomy - age most recent dx
182	p3f4q46	Num	8	BEST12.	BEST32.	Deep vein thrombosis (DVT) - Ever present in timeframe
183	p3f4q46_2dys	Num	8	BEST12.	BEST32.	Deep vein thrombosis (DVT) - date most recent dx
184	p3f4q46_4	Num	8	BEST12.	BEST32.	Deep vein thrombosis (DVT) - age most recent dx
185	p3f4q46a	Num	8	BEST12.	BEST32.	a. Pulmonary embolism
186	p3f4q46a_2dys	Num	8	BEST12.	BEST32.	a. Pulmonary embolism - date most recent dx
187	p3f4q46a_3__1	Num	8	BEST12.	BEST32.	a. Pulmonary embolism -Currently receiving treatment
188	p3f4q46a_4	Num	8	BEST12.	BEST32.	a. Pulmonary embolism - age most recent dx

Num	Variable	Type	Len	Format	Informat	Label
189	p3f4q46b	Num	8	BEST12.	BEST32.	b. Venous thromboembolism (VTE)
190	p3f4q46b_2dys	Num	8	BEST12.	BEST32.	b. Venous thromboembolism (VTE) - date most recent dx
191	p3f4q46b_3___1	Num	8	BEST12.	BEST32.	b. Venous thromboembolism (VTE) -Currently receiving treatment
192	p3f4q46b_4	Num	8	BEST12.	BEST32.	b. Venous thromboembolism (VTE) - age most recent dx
193	p3f4q47	Num	8	BEST12.	BEST32.	Lupus
194	p3f4q47_2dys	Num	8	BEST12.	BEST32.	Lupus - date most recent dx
195	p3f4q47_4	Num	8	BEST12.	BEST32.	Lupus - age most recent dx
196	p3f4q48	Num	8	BEST12.	BEST32.	Rheumatoid arthritis
197	p3f4q48_2dys	Num	8	BEST12.	BEST32.	Rheumatoid arthritis - date most recent dx
198	p3f4q48_4	Char	1	\$1.	\$1.	Rheumatoid arthritis - age most recent dx
199	p3f4q49	Num	8	BEST12.	BEST32.	Gout
200	p3f4q49_2dys	Num	8	BEST12.	BEST32.	Gout - date most recent dx
201	p3f4q49_4	Num	8	BEST12.	BEST32.	Gout - age most recent dx
202	p3f4q50	Num	8	BEST12.	BEST32.	Sarcoidosis
203	p3f4q50_2dys	Num	8	BEST12.	BEST32.	Sarcoidosis - date most recent dx
204	p3f4q50_4	Num	8	BEST12.	BEST32.	Sarcoidosis - age most recent dx
205	p3f4q51___1	Num	8	BEST12.	BEST32.	Chronic kidney disease -Currently receiving treatment
206	p3f4q52	Num	8	BEST12.	BEST32.	Multi-organ failure
207	p3f4q52_2dys	Num	8	BEST12.	BEST32.	Multi-organ failure - date most recent dx
208	p3f4q52_4	Num	8	BEST12.	BEST32.	Multi-organ failure - age most recent dx
209	p3f4q52a___1	Num	8	BEST12.	BEST32.	Multi-organ failure -Received this treatment: ICU
210	p3f4q52b___1	Num	8	BEST12.	BEST32.	Multi-organ failure -Received this treatment: Intubation
211	p3f4q52c___1	Num	8	BEST12.	BEST32.	Multi-organ failure -Received this treatment: Simple Transfusion
212	p3f4q52d___1	Num	8	BEST12.	BEST32.	Multi-organ failure -Received this treatment: Exchange Transfusion
213	p3f4q52e___1	Num	8	BEST12.	BEST32.	Multi-organ failure -Received this treatment: Hemodialysis
214	p3f4q52f___1	Num	8	BEST12.	BEST32.	Multi-organ failure -Received this treatment: Peritoneal dialysis
215	p3f4q53	Num	8	BEST12.	BEST32.	Pneumococcal sepsis
216	p3f4q53_2dys	Num	8	BEST12.	BEST32.	Pneumococcal sepsis - date most recent dx
217	p3f4q53_4	Num	8	BEST12.	BEST32.	Pneumococcal sepsis - age most recent dx
218	p3f4q54	Num	8	BEST12.	BEST32.	Skin ulcers
219	p3f4q54_2dys	Num	8	BEST12.	BEST32.	Skin ulcers - date most recent dx
220	p3f4q54_4	Num	8	BEST12.	BEST32.	Skin ulcers - age most recent dx
221	p3f4q55	Num	8	BEST12.	BEST32.	Retinopathy
222	p3f4q55_2dys	Num	8	BEST12.	BEST32.	Retinopathy - date most recent dx
223	p3f4q55_4	Num	8	BEST12.	BEST32.	Retinopathy - age most recent dx
224	p3f4q56	Num	8	BEST12.	BEST32.	Diabetes mellitus
225	p3f4q56_2dys	Num	8	BEST12.	BEST32.	Diabetes mellitus - date most recent dx
226	p3f4q56_4	Num	8	BEST12.	BEST32.	Diabetes mellitus - age most recent dx

Num	Variable	Type	Len	Format	Informat	Label
227	p3f4q57	Num	8	BEST12.	BEST32.	Iron overload (liver iron content > 3 mg/g of dry weight liver on MRI or serum ferritin above 1,000 ng/dL for >3 separate measurements or >18 PRBCs)
228	p3f4q57_2dys	Num	8	BEST12.	BEST32.	Iron overload - date most recent dx
229	p3f4q57_4	Num	8	BEST12.	BEST32.	Iron overload - age most recent dx
230	p3f4q58	Num	8	BEST12.	BEST32.	Chronic refractory pain
231	p3f4q58_2dys	Num	8	BEST12.	BEST32.	Chronic refractory pain - date most recent dx
232	p3f4q58_3dys	Num	8	BEST12.	BEST32.	Seizure disorder - date most recent dx
233	p3f4q58_4	Num	8	BEST12.	BEST32.	Chronic refractory pain - age most recent dx
234	p3f4q59	Num	8	BEST12.	BEST32.	Anxiety
235	p3f4q59_2dys	Num	8	BEST12.	BEST32.	Anxiety - date most recent dx
236	p3f4q59_4	Num	8	BEST12.	BEST32.	Anxiety - age most recent dx
237	p3f4q60	Num	8	BEST12.	BEST32.	Depression
238	p3f4q60_2dys	Num	8	BEST12.	BEST32.	Depression - date most recent dx
239	p3f4q60_4	Num	8	BEST12.	BEST32.	Depression - age most recent dx
240	p3f4q61	Num	8	BEST12.	BEST32.	Other psychiatric disorder
241	p3f4q61_11dys	Num	8	BEST12.	BEST32.	Hepatitis B - date most recent dx
242	p3f4q61_13dys	Num	8	BEST12.	BEST32.	Hepatitis C - date most recent dx
243	p3f4q61_15dys	Num	8	BEST12.	BEST32.	Intrahepatic cholelithiasis - date most recent dx
244	p3f4q61_17dys	Num	8	BEST12.	BEST32.	Hepatic sequestration - date most recent dx
245	p3f4q61_19dys	Num	8	BEST12.	BEST32.	Bridging fibrosis - date most recent dx
246	p3f4q61_20dys	Num	8	BEST12.	BEST32.	Other major health condition - date most recent dx
247	p3f4q61_3dys	Num	8	BEST12.	BEST32.	Other psychiatric disorder - date most recent dx
248	p3f4q61_4	Num	8	BEST12.	BEST32.	Other psychiatric disorder - age most recent dx
249	p3f4q61_7dys	Char	1	\$1.	\$1.	Liver cirrhosis - date most recent dx
250	p3f4q61_9dys	Num	8	BEST12.	BEST32.	Intrahepatic cholelithiasis - date most recent dx
251	p3f4q63__1	Num	8	BEST12.	BEST32.	61. What kind of health insurance or health care coverage does the subject currently have? Private health insurance
252	p3f4q63__2	Num	8	BEST12.	BEST32.	61. What kind of health insurance or health care coverage does the subject currently have? Medicare
253	p3f4q63__3	Num	8	BEST12.	BEST32.	61. What kind of health insurance or health care coverage does the subject currently have? Medicaid, Medical Assistance (MA), the Childrens Health Insurance Program (CHIP), or any kind of state or government-sponsored assistance
254	p3f4q63__4	Num	8	BEST12.	BEST32.	61. What kind of health insurance or health care coverage does the subject currently have? TRICARE or other military health care, including VA health care
255	p3f4q63__5	Num	8	BEST12.	BEST32.	61. What kind of health insurance or health care coverage does the subject currently have? Support from Charities or Donations
256	p3f4q63__6	Num	8	BEST12.	BEST32.	61. What kind of health insurance or health care coverage does the subject currently have? Other type of health insurance, specify
257	p3f4q63__98	Num	8	BEST12.	BEST32.	61. What kind of health insurance or health care coverage does the subject currently have? None

Num	Variable	Type	Len	Format	Informat	Label
258	p3f4q64	Num	8	BEST12.	BEST32.	Seizure disorder
259	p3f4q64_4	Num	8	BEST12.	BEST32.	Seizure disorder - age most recent dx
260	p3f4q65__1	Num	8	BEST12.	BEST32.	End stage renal disease -Currently receiving treatment
261	p3f4q66	Num	8	BEST12.	BEST32.	Liver cirrhosis
262	p3f4q66_4	Char	1	\$1.	\$1.	Liver cirrhosis - age most recent dx
263	p3f4q67	Num	8	BEST12.	BEST32.	Intrahepatic cholelithiasis
264	p3f4q67_4	Num	8	BEST12.	BEST32.	Intrahepatic cholelithiasis - age most recent dx
265	p3f4q68	Num	8	BEST12.	BEST32.	Hepatitis B
266	p3f4q68_4	Num	8	BEST12.	BEST32.	Hepatitis B - age most recent dx
267	p3f4q69	Num	8	BEST12.	BEST32.	Other major health condition
268	p3f4q69_4	Num	8	BEST12.	BEST32.	Other major health condition - age most recent dx
269	p3f4q70__1	Num	8	BEST12.	BEST32.	Priapism -Currently receiving treatment
270	p3f4q71	Num	8	BEST12.	BEST32.	Hepatitis C
271	p3f4q71_4	Num	8	BEST12.	BEST32.	Hepatitis C - age most recent dx
272	p3f4q72	Num	8	BEST12.	BEST32.	Intrahepatic cholelithiasis
273	p3f4q72_4	Num	8	BEST12.	BEST32.	Intrahepatic cholelithiasis - age most recent dx
274	p3f4q73	Num	8	BEST12.	BEST32.	Has the subject ever been evaluated for curative gene therapy?
275	p3f4q74	Num	8	BEST12.	BEST32.	Hepatic sequestration
276	p3f4q74_4	Num	8	BEST12.	BEST32.	Hepatic sequestration - age most recent dx
277	p3f4q75	Num	8	BEST12.	BEST32.	Bridging fibrosis
278	p3f4q75_4	Char	1	\$1.	\$1.	Bridging fibrosis - age most recent dx
279	p3f4q76__1	Num	8	BEST12.	BEST32.	Stroke -Currently receiving treatment
280	p3f4q77__1	Num	8	BEST12.	BEST32.	Intracranial bleeding -Currently receiving treatment
281	p3f4q78__1	Num	8	BEST12.	BEST32.	Pulmonary arterial hypertension -Currently receiving treatment
282	p3f4q79__1	Num	8	BEST12.	BEST32.	Left ventricular dysfunction -Currently receiving treatment
283	p3f4q80__1	Num	8	BEST12.	BEST32.	Acute chest syndrome -Currently receiving treatment
284	p3f4q81__1	Num	8	BEST12.	BEST32.	Asthma -Currently receiving treatment
285	p3f4q82__1	Num	8	BEST12.	BEST32.	Gallstones/cholelithiasis, cholecystitis -Currently receiving treatment
286	p3f4q83__1	Num	8	BEST12.	BEST32.	Splenomegaly -Currently receiving treatment
287	p3f4q84__1	Num	8	BEST12.	BEST32.	Deep vein thrombosis (DVT) -Currently receiving treatment
288	p3f4q85__1	Num	8	BEST12.	BEST32.	Lupus -Currently receiving treatment
289	p3f4q86__1	Num	8	BEST12.	BEST32.	Rheumatoid arthritis -Currently receiving treatment
290	p3f4q87__1	Num	8	BEST12.	BEST32.	Gout -Currently receiving treatment
291	p3f4q88__1	Num	8	BEST12.	BEST32.	Sarcoidosis -Currently receiving treatment
292	p3f4q89__1	Num	8	BEST12.	BEST32.	Pneumococcal sepsis -Currently receiving treatment
293	p3f4q90__1	Num	8	BEST12.	BEST32.	Skin ulcers -Currently receiving treatment
294	p3f4q91__1	Num	8	BEST12.	BEST32.	Retinopathy -Currently receiving treatment
295	p3f4q92__1	Num	8	BEST12.	BEST32.	Diabetes mellitus -Currently receiving treatment
296	p3f4q93__1	Num	8	BEST12.	BEST32.	Iron overload -Currently receiving treatment

Num	Variable	Type	Len	Format	Informat	Label
297	p3f4q94__1	Num	8	BEST12.	BEST32.	Chronic refractory pain -Currently receiving treatment
298	p3f4q95__1	Num	8	BEST12.	BEST32.	Seizure disorder -Currently receiving treatment
299	p3f4q96__1	Num	8	BEST12.	BEST32.	Anxiety -Currently receiving treatment
300	p3f4q97__1	Num	8	BEST12.	BEST32.	Depression -Currently receiving treatment
301	p3f4q98__1	Num	8	BEST12.	BEST32.	Other psychiatric disorder -Currently receiving treatment
302	p3f4q99__1	Num	8	BEST12.	BEST32.	Other major health condition -Currently receiving treatment

Data Set Name: scdicii_mra_yr1fu.sas7bdat

Num	Variable	Type	Len	Format	Informat	Label
1	newid	Char	8	\$8.	\$8.	Subject ID
2	site	Num	8	BEST12.	BEST32.	Site
3	p3f4q00a_1dys	Num	8	BEST12.	BEST32.	Date patient last known to be alive
4	p3f4q00a_2dys	Num	8	BEST12.	BEST32.	Date last abstraction form completed
5	p3f4q00a_3dys	Num	8	BEST12.	BEST32.	Date through which data abstracted
6	p3f4q00adys	Num	8	BEST12.	BEST32.	Date this form completed
7	p3f4q01	Num	8	BEST12.	BEST32.	Has the subject received a bone marrow transplant(BMT) since the date of the last abstraction?
8	p3f4q01dys	Num	8	BEST12.	BEST32.	Bone marrow transplant date
9	p3f4q03	Num	8	BEST12.	BEST32.	Confirmed enrollment diagnosis: Diagnosis must be supported by source documentation.
10	p3f4q03a	Num	8	BEST12.	BEST32.	What was the basis for diagnosis?
11	p3f4q04	Num	8	BEST12.	BEST32.	Approximate age of first diagnosis (physician confirmed)
12	p3f4q04a	Num	8	BEST12.	BEST32.	Age of first diagnosis in years
13	p3f4q04b___1	Num	8	BEST12.	BEST32.	Medical records not available, form complete
14	p3f4q05	Num	8	BEST12.	BEST32.	Test results for alpha-thalassemia since the date of last abstraction?
15	p3f4q06_1	Num	8	BEST12.	BEST32.	4. Height (CM):Measurements
16	p3f4q06_2dys	Num	8	BEST12.	BEST32.	4. Height: date
17	p3f4q06_3	Num	8	BEST12.	BEST32.	4. Height: Steady state?
18	p3f4q06___1	Num	8	BEST12.	BEST32.	4. Height (CM): Not in record
19	p3f4q07_1	Num	8	BEST12.	BEST32.	5. Weight(KG): Measurements
20	p3f4q07_2dys	Num	8	BEST12.	BEST32.	5. Weight: date
21	p3f4q07_3	Num	8	BEST12.	BEST32.	5. Weight: Steady state?
22	p3f4q07___1	Num	8	BEST12.	BEST32.	5. Weight(KG): Not in record
23	p3f4q08_1	Num	8	BEST12.	BEST32.	6. Temperature (Celsius):Measurements
24	p3f4q08_2dys	Num	8	BEST12.	BEST32.	6. Temperature: date
25	p3f4q08_3	Num	8	BEST12.	BEST32.	6. Temperature: Steady state?
26	p3f4q08___1	Num	8	BEST12.	BEST32.	6. Temperature (Celsius): Not in record
27	p3f4q09_1	Num	8	BEST12.	BEST32.	7. Heart Rate (Beats/Minute):Measurements
28	p3f4q09_2dys	Num	8	BEST12.	BEST32.	7. Heart Rate: date
29	p3f4q09_3	Num	8	BEST12.	BEST32.	7. Heart Rate: Steady state?
30	p3f4q09___1	Num	8	BEST12.	BEST32.	7. Heart Rate (Beats/Minute): Not in record
31	p3f4q100___1	Num	8	BEST12.	BEST32.	Liver cirrhosis -Received treatment in timeframe
32	p3f4q101___1	Num	8	BEST12.	BEST32.	Intrahepatic cholelithiasis -Received treatment in timeframe
33	p3f4q102___1	Num	8	BEST12.	BEST32.	Hepatitis B -Received treatment in timeframe
34	p3f4q103___1	Num	8	BEST12.	BEST32.	Hepatitis C -Received treatment in timeframe
35	p3f4q104___1	Num	8	BEST12.	BEST32.	Intrahepatic cholelithiasis -Received treatment in timeframe

Num	Variable	Type	Len	Format	Informat	Label
36	p3f4q105___1	Num	8	BEST12.	BEST32.	Hepatic sequestration -Received treatment in timeframe
37	p3f4q106___1	Num	8	BEST12.	BEST32.	Bridging fibrosis -Received treatment in timeframe
38	p3f4q10_1	Num	8	BEST12.	BEST32.	8. Respiration Rate (Breaths/Minute):Measurements
39	p3f4q10_2dys	Num	8	BEST12.	BEST32.	8. Respiration Rate: date
40	p3f4q10_3	Num	8	BEST12.	BEST32.	8. Respiration Rate :Steady state?
41	p3f4q10___1	Num	8	BEST12.	BEST32.	8. Respiration Rate (Breaths/Minute): Not in record
42	p3f4q11_1	Num	8	BEST12.	BEST32.	9. Oxygen Saturation (SpO2):Measurements
43	p3f4q11_2dys	Num	8	BEST12.	BEST32.	9. Oxygen Saturation: date
44	p3f4q11_3	Num	8	BEST12.	BEST32.	9. Oxygen Saturation: Steady state?
45	p3f4q11___1	Num	8	BEST12.	BEST32.	9. Oxygen Saturation (SpO2): Not in record
46	p3f4q12_1	Num	8	BEST12.	BEST32.	Systolic
47	p3f4q12_2	Num	8	BEST12.	BEST32.	Diastolic
48	p3f4q12_3	Num	8	BEST12.	BEST32.	ON ANTI-HYPERTENSIVE MEDS?
49	p3f4q12_5dys	Num	8	BEST12.	BEST32.	10. Blood Pressure: date
50	p3f4q12_6	Num	8	BEST12.	BEST32.	10. Blood Pressure: Steady state?
51	p3f4q12___1	Num	8	BEST12.	BEST32.	10. Blood Pressure: Not in record
52	p3f4q12_b	Num	8	BEST12.	BEST32.	Is the subject currently taking hydroxyurea?
53	p3f4q12b	Num	8	BEST12.	BEST32.	Subject started or stopped Endari since the date of last abstraction
54	p3f4q12b_adys	Num	8	BEST12.	BEST32.	a. Endari Start date
55	p3f4q12b_b1___1	Num	8	BEST12.	BEST32.	b. Endari Stop/last date =Currently using
56	p3f4q12b_bdys	Num	8	BEST12.	BEST32.	b. Endari Stop/last date
57	p3f4q12b_c	Num	8	BEST12.	BEST32.	c. Endari Total duration of use
58	p3f4q12b_c1	Num	8	BEST12.	BEST32.	Endari Total duration of use Unit
59	p3f4q12b_c2	Num	8	BEST12.	BEST32.	Endari Current dose Unit
60	p3f4q12b_d	Num	8	BEST12.	BEST32.	d. Endari Current dose
61	p3f4q13	Num	8	BEST12.	BEST32.	Subject started or stopped hydroxyurea since the date of last abstraction
62	p3f4q13adys	Num	8	BEST12.	BEST32.	a. Hydroxyurea start date
63	p3f4q13b2	Num	8	BEST12.	BEST32.	Subject started or stopped Adakveo since the date of last abstraction
64	p3f4q13b2_adys	Num	8	BEST12.	BEST32.	b. Hydroxyurea Stop/last date
65	p3f4q13b2_b1___1	Num	8	BEST12.	BEST32.	b. Adakveo Stop/last date =Currently using
66	p3f4q13b2_bdys	Num	8	BEST12.	BEST32.	a. Adakveo Start date
67	p3f4q13b2_c	Num	8	BEST12.	BEST32.	c. Adakveo Total duration of use
68	p3f4q13b2_c1	Num	8	BEST12.	BEST32.	Adakveo Total duration of use Unit
69	p3f4q13b2_c2	Num	8	BEST12.	BEST32.	Adakveo Current dose Unit
70	p3f4q13b2_d	Num	8	BEST12.	BEST32.	d. Adakveo Current dose
71	p3f4q13b3	Num	8	BEST12.	BEST32.	16. Is the subject currently taking Adakveo?
72	p3f4q13b_1___1	Num	8	BEST12.	BEST32.	b. Hydroxyurea Stop/last date= Currently Using
73	p3f4q13bdys	Num	8	BEST12.	BEST32.	b. Adakveo Stop/last date
74	p3f4q13c1	Num	8	BEST12.	BEST32.	Hydroxyurea Total duration of use Unit

Num	Variable	Type	Len	Format	Informat	Label
75	p3f4q13c_2	Num	8	BEST12.	BEST32.	c. Hydroxyurea Total duration of use
76	p3f4q13d	Num	8	BEST12.	BEST32.	d. Hydroxyurea Current dose
77	p3f4q13d_2	Num	8	BEST12.	BEST32.	Hydroxyurea Dose unit
78	p3f4q14_b	Num	8	BEST12.	BEST32.	14. Is the subject currently taking Endari?
79	p3f4q14b	Num	8	BEST12.	BEST32.	Subject started or stopped Oxbryta since the date of last abstraction
80	p3f4q14b_2	Num	8	BEST12.	BEST32.	18. Is the subject currently taking Oxbryta?
81	p3f4q14b_adys	Num	8	BEST12.	BEST32.	a. Oxbryta Start date
82	p3f4q14b_b1___1	Num	8	BEST12.	BEST32.	b. Oxbryta Stop/last date =Currently using
83	p3f4q14b_bdys	Num	8	BEST12.	BEST32.	b. OxbrytaStop/last date
84	p3f4q14b_c	Num	8	BEST12.	BEST32.	c. Oxbryta Total duration of use
85	p3f4q14b_c1	Num	8	BEST12.	BEST32.	Oxbryta Total duration of use Unit
86	p3f4q14b_c2	Num	8	BEST12.	BEST32.	Oxbryta Current dose Unit
87	p3f4q14b_d	Num	8	BEST12.	BEST32.	d. Oxbryta Current dose
88	p3f4q32	Num	8	BEST12.	BEST32.	Avascular necrosis - Ever present in timeframe (check all that apply)
89	p3f4q32_2a	Char	1	\$1.	\$1.	Avascular necrosis - age most recent dx
90	p3f4q32_2dys	Num	8	BEST12.	BEST32.	Avascular necrosis - date most recent dx
91	p3f4q32a	Num	8	BEST12.	BEST32.	AVN hip - Ever present in timeframe
92	p3f4q32a_2dys	Num	8	BEST12.	BEST32.	AVN hip - date most recent dx
93	p3f4q32a_3___1	Num	8	BEST12.	BEST32.	AVN hip -received treatment in timeframe
94	p3f4q32a_4	Char	1	\$1.	\$1.	AVN hip - age most recent dx
95	p3f4q32b	Num	8	BEST12.	BEST32.	AVN shoulder Ever present in timeframe
96	p3f4q32b_2dys	Num	8	BEST12.	BEST32.	AVN shoulder - date most recent dx
97	p3f4q32b_3___1	Num	8	BEST12.	BEST32.	AVN shoulder -Received treatment in timeframe
98	p3f4q32b_4	Char	1	\$1.	\$1.	AVN shoulder - age most recent dx
99	p3f4q32c	Num	8	BEST12.	BEST32.	AVN knee Ever present in timeframe
100	p3f4q32c_2dys	Num	8	BEST12.	BEST32.	AVN knee - date most recent dx
101	p3f4q32c_3___1	Num	8	BEST12.	BEST32.	AVN knee -Received treatment in timeframe
102	p3f4q32c_4	Char	1	\$1.	\$1.	AVN knee - age most recent dx
103	p3f4q32d	Num	8	BEST12.	BEST32.	AVN other location - Ever present in timeframe
104	p3f4q32d_2___1	Num	8	BEST12.	BEST32.	AVN other location -Received treatment in timeframe
105	p3f4q32d_3dys	Num	8	BEST12.	BEST32.	AVN other location - date most recent dx
106	p3f4q32d_4	Char	1	\$1.	\$1.	AVN other location - age most recent dx
107	p3f4q33___1	Num	8	BEST12.	BEST32.	Avascular necrosis -received treatment in timeframe
108	p3f4q35	Num	8	BEST12.	BEST32.	Chronic kidney disease -Ever present in timeframe
109	p3f4q35_2dys	Num	8	BEST12.	BEST32.	Chronic kidney disease - date most recent dx
110	p3f4q35_4	Char	1	\$1.	\$1.	Chronic kidney disease - age most recent dx
111	p3f4q36	Num	8	BEST12.	BEST32.	End stage most recent dx renal disease -Ever present in timeframe
112	p3f4q36_2dys	Num	8	BEST12.	BEST32.	End stage most recent dx renal disease - date most recent dx
113	p3f4q36_4	Char	1	\$1.	\$1.	End stage most recent dx renal disease - age most recent dx

Num	Variable	Type	Len	Format	Informat	Label
114	p3f4q36a	Num	8	BEST12.	BEST32.	Kidney transplant -Ever present in timeframe
115	p3f4q36a_2dys	Char	1	\$1.	\$1.	Kidney transplant - date most recent dx
116	p3f4q36a_3	Num	8	BEST12.	BEST32.	Kidney transplant rejection
117	p3f4q36a_3b___1	Num	8	BEST12.	BEST32.	Kidney transplant -Received treatment in timeframe
118	p3f4q36a_4	Char	1	\$1.	\$1.	Kidney transplant - age most recent dx
119	p3f4q37	Num	8	BEST12.	BEST32.	Priapism -Ever present in timeframe
120	p3f4q37_2dys	Num	8	BEST12.	BEST32.	Priapism - date most recent dx
121	p3f4q37_4	Char	1	\$1.	\$1.	Priapism - age most recent dx
122	p3f4q38	Num	8	BEST12.	BEST32.	Stroke -Ever present in timeframe (check all that apply)
123	p3f4q38_2dys	Num	8	BEST12.	BEST32.	Stroke - date most recent dx
124	p3f4q38_4	Char	1	\$1.	\$1.	Stroke - age most recent dx
125	p3f4q38a	Num	8	BEST12.	BEST32.	Stroke ischemic -Ever present in timeframe
126	p3f4q38a_2dys	Num	8	BEST12.	BEST32.	Stroke ischemic - date most recent dx
127	p3f4q38a_3___1	Num	8	BEST12.	BEST32.	Stroke ischemic -Received treatment in timeframe
128	p3f4q38a_4	Char	1	\$1.	\$1.	Stroke ischemic - age most recent dx
129	p3f4q38b	Num	8	BEST12.	BEST32.	Stroke hemorrhagic -Ever present in timeframe
130	p3f4q38b_2dys	Num	8	BEST12.	BEST32.	Stroke hemorrhagic - date most recent dx
131	p3f4q38b_3___1	Num	8	BEST12.	BEST32.	Stroke hemorrhagic -Received treatment in timeframe
132	p3f4q38b_4	Char	1	\$1.	\$1.	Stroke hemorrhagic - age most recent dx
133	p3f4q38c	Num	8	BEST12.	BEST32.	Stroke Transient ischemic attack (TIA) -Ever present in timeframe
134	p3f4q38c_2dys	Num	8	BEST12.	BEST32.	Stroke Transient ischemic attack (TIA) - date most recent dx
135	p3f4q38c_3___1	Num	8	BEST12.	BEST32.	Stroke Transient ischemic attack (TIA) -Received treatment in timeframe
136	p3f4q38c_4	Char	1	\$1.	\$1.	Stroke Transient ischemic attack (TIA) - age most recent dx
137	p3f4q38d	Num	8	BEST12.	BEST32.	Stroke ischemic -Ever present in timeframe (check all that apply)
138	p3f4q38d_2dys	Num	8	BEST12.	BEST32.	Stroke ischemic - date most recent dx
139	p3f4q38d_3___1	Num	8	BEST12.	BEST32.	Stroke ischemic -Received treatment in timeframe
140	p3f4q38d_4	Char	1	\$1.	\$1.	Stroke ischemic - age most recent dx
141	p3f4q39	Num	8	BEST12.	BEST32.	Intracranial bleeding -Ever present in timeframe
142	p3f4q39_2dys	Num	8	BEST12.	BEST32.	Intracranial bleeding - date most recent dx
143	p3f4q39_4	Char	1	\$1.	\$1.	Intracranial bleeding - age most recent dx
144	p3f4q40	Num	8	BEST12.	BEST32.	Pulmonary arterial hypertension -Ever present in timeframe
145	p3f4q40_2dys	Num	8	BEST12.	BEST32.	Pulmonary arterial hypertension - date most recent dx
146	p3f4q40_4	Char	1	\$1.	\$1.	Pulmonary arterial hypertension - age most recent dx
147	p3f4q40a	Num	8	BEST12.	BEST32.	a. Mean pulmonary artery pressure > or = to 25 mm Hg -Ever present in timeframe
148	p3f4q40a_2dys	Num	8	BEST12.	BEST32.	a. Mean pulmonary artery pressure > or = to 25 mm Hg - date most recent dx
149	p3f4q40a_3___1	Num	8	BEST12.	BEST32.	a. Mean pulmonary artery pressure > or = to 25 mm Hg -Received treatment in timeframe

Num	Variable	Type	Len	Format	Informat	Label
150	p3f4q40a_4	Char	1	\$1.	\$1.	a. Mean pulmonary artery pressure > or = to 25 mm Hg - age most recent dx
151	p3f4q40b	Num	8	BEST12.	BEST32.	b. Tricuspid regurgitation velocity (TRV) > or = to 3. 0 m/sec -Ever present in timeframe
152	p3f4q40b_2dys	Num	8	BEST12.	BEST32.	b. Tricuspid regurgitation velocity (TRV) > or = to 3. 0 m/sec - date most recent dx
153	p3f4q40b_3___1	Num	8	BEST12.	BEST32.	b. Tricuspid regurgitation velocity (TRV) > or = to 3. 0 m/sec -Received treatment in timeframe
154	p3f4q40b_4	Char	1	\$1.	\$1.	b. Tricuspid regurgitation velocity (TRV) > or = to 3. 0 m/sec - age most recent dx
155	p3f4q41	Num	8	BEST12.	BEST32.	Left ventricular dysfunction -Ever present in timeframe
156	p3f4q41_2dys	Num	8	BEST12.	BEST32.	Left ventricular dysfunction - date most recent dx
157	p3f4q41_4	Char	1	\$1.	\$1.	Left ventricular dysfunction - age most recent dx
158	p3f4q42	Num	8	BEST12.	BEST32.	Acute chest syndrome -Ever present in timeframe
159	p3f4q42_2dys	Num	8	BEST12.	BEST32.	Acute chest syndrome - date most recent dx
160	p3f4q42_4	Char	1	\$1.	\$1.	Acute chest syndrome - age most recent dx
161	p3f4q43	Num	8	BEST12.	BEST32.	Asthma -Ever present in timeframe
162	p3f4q43_2dys	Num	8	BEST12.	BEST32.	Asthma - date most recent dx
163	p3f4q43_4	Char	1	\$1.	\$1.	Asthma - age most recent dx
164	p3f4q44	Num	8	BEST12.	BEST32.	Gallstones/cholelithiasis, cholecystitis -Ever present in timeframe
165	p3f4q44_2dys	Num	8	BEST12.	BEST32.	Gallstones/cholelithiasis, cholecystitis - date most recent dx
166	p3f4q44_4	Char	1	\$1.	\$1.	Gallstones/cholelithiasis, cholecystitis - age most recent dx
167	p3f4q45	Num	8	BEST12.	BEST32.	Splenomegaly -Ever present in timeframe (check all that apply)
168	p3f4q45_2dys	Num	8	BEST12.	BEST32.	Splenomegaly - date most recent dx
169	p3f4q45_4_2	Char	1	\$1.	\$1.	Splenomegaly - age most recent dx
170	p3f4q45_4dys	Num	8	BEST12.	BEST32.	Splenic sequestration - date most recent dx
171	p3f4q45_5	Num	8	BEST12.	BEST32.	# sequestration episodes in past 12 months
172	p3f4q45a	Num	8	BEST12.	BEST32.	a. PRBC transfusion given for splenomegaly?
173	p3f4q45b	Num	8	BEST12.	BEST32.	b. Splenic sequestration - Ever present in timeframe
174	p3f4q45b_2dys	Num	8	BEST12.	BEST32.	Splenic infarcts - date most recent dx
175	p3f4q45b_3	Num	8	BEST12.	BEST32.	c. Splenic infarcts, symptomatic
176	p3f4q45b_3_4	Char	1	\$1.	\$1.	Splenic infarcts - age most recent dx
177	p3f4q45b_4___1	Num	8	BEST12.	BEST32.	Splenic sequestration -Received treatment in timeframe
178	p3f4q45b_5___1	Num	8	BEST12.	BEST32.	Splenic infarcts -Received treatment in timeframe
179	p3f4q45b_6	Char	1	\$1.	\$1.	Splenic sequestration - age most recent dx
180	p3f4q45c	Num	8	BEST12.	BEST32.	d. Hypersplenism- Ever present in timeframe
181	p3f4q45c_2dys	Num	8	BEST12.	BEST32.	Hypersplenism - date most recent dx
182	p3f4q45c_3___1	Num	8	BEST12.	BEST32.	Hypersplenism -Received treatment in timeframe
183	p3f4q45c_4	Char	1	\$1.	\$1.	Hypersplenism - age most recent dx
184	p3f4q45d	Num	8	BEST12.	BEST32.	e. Splenectomy- Ever present in timeframe

Num	Variable	Type	Len	Format	Informat	Label
185	p3f4q45d_2dys	Num	8	BEST12.	BEST32.	Splenectomy - date most recent dx
186	p3f4q45d_4	Char	1	\$1.	\$1.	Splenectomy - age most recent dx
187	p3f4q46	Num	8	BEST12.	BEST32.	Deep vein thrombosis (DVT) - Ever present in timeframe
188	p3f4q46_2dys	Num	8	BEST12.	BEST32.	Deep vein thrombosis (DVT) - date most recent dx
189	p3f4q46_4	Char	1	\$1.	\$1.	Deep vein thrombosis (DVT) - age most recent dx
190	p3f4q46a	Num	8	BEST12.	BEST32.	a. Pulmonary embolism- Ever present in timeframe
191	p3f4q46a_2dys	Num	8	BEST12.	BEST32.	a. Pulmonary embolism - date most recent dx
192	p3f4q46a_3___1	Num	8	BEST12.	BEST32.	a. Pulmonary embolism -Received treatment in timeframe
193	p3f4q46a_4	Char	1	\$1.	\$1.	a. Pulmonary embolism - age most recent dx
194	p3f4q46b	Num	8	BEST12.	BEST32.	b. Venous thromboembolism (VTE)- Ever present in timeframe
195	p3f4q46b_2dys	Num	8	BEST12.	BEST32.	b. Venous thromboembolism (VTE) - date most recent dx
196	p3f4q46b_3___1	Num	8	BEST12.	BEST32.	b. Venous thromboembolism (VTE) -Received treatment in timeframe
197	p3f4q46b_4	Char	1	\$1.	\$1.	b. Venous thromboembolism (VTE) - age most recent dx
198	p3f4q47	Num	8	BEST12.	BEST32.	Lupus- Ever present in timeframe
199	p3f4q47_2dys	Num	8	BEST12.	BEST32.	Lupus - date most recent dx
200	p3f4q47_4	Char	1	\$1.	\$1.	Lupus - age most recent dx
201	p3f4q48	Num	8	BEST12.	BEST32.	Rheumatoid arthritis- Ever present in timeframe
202	p3f4q48_2dys	Num	8	BEST12.	BEST32.	Rheumatoid arthritis - date most recent dx
203	p3f4q48_4	Char	1	\$1.	\$1.	Rheumatoid arthritis - age most recent dx
204	p3f4q49	Num	8	BEST12.	BEST32.	Gout- Ever present in timeframe
205	p3f4q49_2dys	Num	8	BEST12.	BEST32.	Gout - date most recent dx
206	p3f4q49_4	Char	1	\$1.	\$1.	Gout - age most recent dx
207	p3f4q50	Num	8	BEST12.	BEST32.	Sarcoidosis- Ever present in timeframe
208	p3f4q50_2dys	Char	1	\$1.	\$1.	Sarcoidosis - date most recent dx
209	p3f4q50_4	Char	1	\$1.	\$1.	Sarcoidosis - age most recent dx
210	p3f4q51___1	Num	8	BEST12.	BEST32.	Chronic kidney disease -Received treatment in timeframe
211	p3f4q52	Num	8	BEST12.	BEST32.	Multi-organ failure - Ever present in timeframe
212	p3f4q52_2dys	Num	8	BEST12.	BEST32.	Multi-organ failure - date most recent dx
213	p3f4q52_4	Char	1	\$1.	\$1.	Multi-organ failure - age most recent dx
214	p3f4q52a___1	Num	8	BEST12.	BEST32.	Multi-organ failure -Received this treatment: ICU
215	p3f4q52b___1	Num	8	BEST12.	BEST32.	Multi-organ failure -Received this treatment: Intubation
216	p3f4q52c___1	Num	8	BEST12.	BEST32.	Multi-organ failure -Received this treatment: Simple Transfusion
217	p3f4q52d___1	Num	8	BEST12.	BEST32.	Multi-organ failure -Received this treatment: Exchange Transfusion
218	p3f4q52e___1	Num	8	BEST12.	BEST32.	Multi-organ failure -Received this treatment: Hemodialysis
219	p3f4q52f___1	Num	8	BEST12.	BEST32.	Multi-organ failure -Received this treatment: Peritoneal dialysis
220	p3f4q53	Num	8	BEST12.	BEST32.	Pneumococcal sepsis- Ever present in timeframe
221	p3f4q53_2dys	Num	8	BEST12.	BEST32.	Pneumococcal sepsis - date most recent dx
222	p3f4q53_4	Char	1	\$1.	\$1.	Pneumococcal sepsis - age most recent dx
223	p3f4q54	Num	8	BEST12.	BEST32.	Skin ulcers- Ever present in timeframe

Num	Variable	Type	Len	Format	Informat	Label
224	p3f4q54_2dys	Num	8	BEST12.	BEST32.	Skin ulcers - date most recent dx
225	p3f4q54_4	Char	1	\$1.	\$1.	Skin ulcers - age most recent dx
226	p3f4q55	Num	8	BEST12.	BEST32.	Retinopathy- Ever present in timeframe
227	p3f4q55_2dys	Num	8	BEST12.	BEST32.	Retinopathy - date most recent dx
228	p3f4q55_4	Char	1	\$1.	\$1.	Retinopathy - age most recent dx
229	p3f4q56	Num	8	BEST12.	BEST32.	Diabetes mellitus- Ever present in timeframe
230	p3f4q56_2dys	Num	8	BEST12.	BEST32.	Diabetes mellitus - date most recent dx
231	p3f4q56_4	Char	1	\$1.	\$1.	Diabetes mellitus - age most recent dx
232	p3f4q57	Num	8	BEST12.	BEST32.	Iron overload (liver iron content > 3 mg/g of dry weight liver on MRI or serum ferritin above 1,000 ng/dL for >3 separate measurements or >18 PRBCs)- Ever present in timeframe
233	p3f4q57_2dys	Num	8	BEST12.	BEST32.	Iron overload - date most recent dx
234	p3f4q57_4	Char	1	\$1.	\$1.	Iron overload - age most recent dx
235	p3f4q58	Num	8	BEST12.	BEST32.	Chronic refractory pain- Ever present in timeframe
236	p3f4q58_2dys	Num	8	BEST12.	BEST32.	Chronic refractory pain - date most recent dx
237	p3f4q58_3dys	Num	8	BEST12.	BEST32.	Seizure disorder - date most recent dx
238	p3f4q58_4	Char	1	\$1.	\$1.	Chronic refractory pain - age most recent dx
239	p3f4q59	Num	8	BEST12.	BEST32.	Anxiety- Ever present in timeframe
240	p3f4q59_2dys	Num	8	BEST12.	BEST32.	Anxiety - date most recent dx
241	p3f4q59_4	Char	1	\$1.	\$1.	Anxiety - age most recent dx
242	p3f4q60	Num	8	BEST12.	BEST32.	Depression- Ever present in timeframe
243	p3f4q60_2dys	Num	8	BEST12.	BEST32.	Depression - date most recent dx
244	p3f4q60_4	Char	1	\$1.	\$1.	Depression - age most recent dx
245	p3f4q61	Num	8	BEST12.	BEST32.	Other psychiatric disorder- Ever present in timeframe
246	p3f4q61_11dys	Num	8	BEST12.	BEST32.	Hepatitis B - date most recent dx
247	p3f4q61_13dys	Num	8	BEST12.	BEST32.	Hepatitis C - date most recent dx
248	p3f4q61_15dys	Num	8	BEST12.	BEST32.	Intrahepatic cholelithiasis - date most recent dx
249	p3f4q61_17dys	Num	8	BEST12.	BEST32.	Hepatic sequestration - date most recent dx
250	p3f4q61_19dys	Num	8	BEST12.	BEST32.	Bridging fibrosis - date most recent dx
251	p3f4q61_20dys	Num	8	BEST12.	BEST32.	Other major health condition - date most recent dx
252	p3f4q61_3dys	Num	8	BEST12.	BEST32.	Other psychiatric disorder - date most recent dx
253	p3f4q61_4	Char	1	\$1.	\$1.	Other psychiatric disorder - age most recent dx
254	p3f4q61_7dys	Num	8	BEST12.	BEST32.	Liver cirrhosis - date most recent dx
255	p3f4q61_9dys	Num	8	BEST12.	BEST32.	Intrahepatic cholelithiasis - date most recent dx
256	p3f4q63__1	Num	8	BEST12.	BEST32.	61. What kind of health insurance or health care coverage does the subject currently have? Private health insurance
257	p3f4q63__2	Num	8	BEST12.	BEST32.	61. What kind of health insurance or health care coverage does the subject currently have? Medicare

Num	Variable	Type	Len	Format	Informat	Label
258	p3f4q63__3	Num	8	BEST12.	BEST32.	61. What kind of health insurance or health care coverage does the subject currently have? Medicaid, Medical Assistance (MA), the Childrens Health Insurance Program (CHIP), or any kind of state or government-sponsored assistance
259	p3f4q63__4	Num	8	BEST12.	BEST32.	61. What kind of health insurance or health care coverage does the subject currently have? TRICARE or other military health care, including VA health care
260	p3f4q63__5	Num	8	BEST12.	BEST32.	61. What kind of health insurance or health care coverage does the subject currently have? Support from Charities or Donations
261	p3f4q63__6	Num	8	BEST12.	BEST32.	61. What kind of health insurance or health care coverage does the subject currently have? Other type of health insurance, specify
262	p3f4q63__98	Num	8	BEST12.	BEST32.	61. What kind of health insurance or health care coverage does the subject currently have? None
263	p3f4q64	Num	8	BEST12.	BEST32.	Seizure disorder- Ever present in timeframe
264	p3f4q64_4	Char	1	\$1.	\$1.	Seizure disorder - age most recent dx
265	p3f4q65__1	Num	8	BEST12.	BEST32.	End stage most recent dx renal disease -Received treatment in timeframe
266	p3f4q66	Num	8	BEST12.	BEST32.	Liver cirrhosis- Ever present in timeframe
267	p3f4q66_4	Char	1	\$1.	\$1.	Liver cirrhosis - age most recent dx
268	p3f4q67	Num	8	BEST12.	BEST32.	Intrahepatic cholelithiasis- Ever present in timeframe
269	p3f4q67_4	Char	1	\$1.	\$1.	Intrahepatic cholelithiasis - age most recent dx
270	p3f4q68	Num	8	BEST12.	BEST32.	Hepatitis B- Ever present in timeframe
271	p3f4q68_4	Char	1	\$1.	\$1.	Hepatitis B - age most recent dx
272	p3f4q69	Num	8	BEST12.	BEST32.	Other major health condition- Ever present in timeframe
273	p3f4q69_4	Char	1	\$1.	\$1.	Other major health condition - age most recent dx
274	p3f4q70__1	Num	8	BEST12.	BEST32.	Priapism -Received treatment in timeframe
275	p3f4q71	Num	8	BEST12.	BEST32.	Hepatitis C- Ever present in timeframe
276	p3f4q71_4	Char	1	\$1.	\$1.	Hepatitis C - age most recent dx
277	p3f4q72	Num	8	BEST12.	BEST32.	Intrahepatic cholelithiasis- Ever present in timeframe
278	p3f4q72_4	Char	1	\$1.	\$1.	Intrahepatic cholelithiasis - age most recent dx
279	p3f4q73	Num	8	BEST12.	BEST32.	Has the subject been evaluated for curative gene therapy since the date of the last abstraction?
280	p3f4q74	Num	8	BEST12.	BEST32.	Hepatic sequestration- Ever present in timeframe
281	p3f4q74_4	Char	1	\$1.	\$1.	Hepatic sequestration - age most recent dx
282	p3f4q75	Num	8	BEST12.	BEST32.	Bridging fibrosis- Ever present in timeframe
283	p3f4q75_4	Char	1	\$1.	\$1.	Bridging fibrosis - age most recent dx
284	p3f4q76__1	Num	8	BEST12.	BEST32.	Stroke -Received treatment in timeframe
285	p3f4q77__1	Num	8	BEST12.	BEST32.	Intracranial bleeding -Received treatment in timeframe
286	p3f4q78__1	Num	8	BEST12.	BEST32.	Pulmonary arterial hypertension -Received treatment in timeframe
287	p3f4q79__1	Num	8	BEST12.	BEST32.	Left ventricular dysfunction -Received treatment in timeframe
288	p3f4q80__1	Num	8	BEST12.	BEST32.	Acute chest syndrome -Received treatment in timeframe
289	p3f4q81__1	Num	8	BEST12.	BEST32.	Asthma -Received treatment in timeframe
290	p3f4q82__1	Num	8	BEST12.	BEST32.	Gallstones/cholelithiasis, cholecystitis -Received treatment in timeframe

Num	Variable	Type	Len	Format	Informat	Label
291	p3f4q83__1	Num	8	BEST12.	BEST32.	Splenomegaly -Received treatment in timeframe
292	p3f4q84__1	Num	8	BEST12.	BEST32.	Deep vein thrombosis (DVT) -Received treatment in timeframe
293	p3f4q85__1	Num	8	BEST12.	BEST32.	Lupus -Received treatment in timeframe
294	p3f4q86__1	Num	8	BEST12.	BEST32.	Rheumatoid arthritis -Received treatment in timeframe
295	p3f4q87__1	Num	8	BEST12.	BEST32.	Gout -Received treatment in timeframe
296	p3f4q88__1	Num	8	BEST12.	BEST32.	Sarcoidosis -Received treatment in timeframe
297	p3f4q89__1	Num	8	BEST12.	BEST32.	Pneumococcal sepsis -Received treatment in timeframe
298	p3f4q90__1	Num	8	BEST12.	BEST32.	Skin ulcers -Received treatment in timeframe
299	p3f4q91__1	Num	8	BEST12.	BEST32.	Retinopathy -Received treatment in timeframe
300	p3f4q92__1	Num	8	BEST12.	BEST32.	Diabetes mellitus -Received treatment in timeframe
301	p3f4q93__1	Num	8	BEST12.	BEST32.	Iron overload -Received treatment in timeframe
302	p3f4q94__1	Num	8	BEST12.	BEST32.	Chronic refractory pain -Received treatment in timeframe
303	p3f4q95__1	Num	8	BEST12.	BEST32.	Seizure disorder -Received treatment in timeframe
304	p3f4q96__1	Num	8	BEST12.	BEST32.	Anxiety -Received treatment in timeframe
305	p3f4q97__1	Num	8	BEST12.	BEST32.	Depression -Received treatment in timeframe
306	p3f4q98__1	Num	8	BEST12.	BEST32.	Other psychiatric disorder -Received treatment in timeframe
307	p3f4q99__1	Num	8	BEST12.	BEST32.	Other major health condition -Received treatment in timeframe

Data Set Name: scdicii_procedures_yr1.sas7bdat

Num	Variable	Type	Len	Format	Informat	Label
1	newid	Char	8	\$8.	\$8.	Subject ID
2	site	Num	8	BEST12.	BEST32.	Site
3	p1f10_dtdys	Num	8	BEST12.	BEST32.	Date this form completed
4	p1f10q01	Num	8	BEST12.	BEST32.	1. Was a liver biopsy ever done?
5	p1f10q01_dtdys	Num	8	BEST12.	BEST32.	1. Date of Most Recent Biopsy
6	p1f10q01b	Num	8	BEST12.	BEST32.	1b. What was the result/diagnosis of the biopsy?
7	p1f10q02	Num	8	BEST12.	BEST32.	2. Was an MRI of the liver ever done?
8	p1f10q02_dtdys	Num	8	BEST12.	BEST32.	2. Date of Most Recent Liver MRI
9	p1f10q02b	Num	8	BEST12.	BEST32.	2b. If yes, what was the MRI method?
10	p1f10q02c	Num	8	BEST12.	BEST32.	2c. What was the liver iron content (LIC)?
11	p1f10q03	Num	8	BEST12.	BEST32.	3. Was a cardiac MRI ever done?
12	p1f10q03_dtdys	Num	8	BEST12.	BEST32.	3. Date of Most Recent Cardiac MRI
13	p1f10q03b	Num	8	BEST12.	BEST32.	3b. What was the result/diagnosis of the Cardiac MRI?
14	p1f10q04	Num	8	BEST12.	BEST32.	4. Was a cardiac ECHO ever done?
15	p1f10q04_dtdys	Num	8	BEST12.	BEST32.	4. Date of Most Recent Cardiac ECHO
16	p1f10q05	Num	8	BEST12.	BEST32.	5. Was a cardiac EKG ever done?
17	p1f10q05_dtdys	Num	8	BEST12.	BEST32.	5. Date of Most Recent Procedure
18	p1f10q06	Num	8	BEST12.	BEST32.	6. Was a cardiac catheterization ever done?
19	p1f10q06_dtdys	Num	8	BEST12.	BEST32.	6. Date of Most Recent cardiac catheterization
20	p1f10q07	Num	8	BEST12.	BEST32.	7. Was an MRI of the brain ever done?
21	p1f10q07_dtdys	Num	8	BEST12.	BEST32.	7. Date of Most Recent MRI of the brain
22	p1f10q07b	Num	8	BEST12.	BEST32.	7b. What was the result/diagnosis of the MRI of the brain?
23	p1f10q08	Num	8	BEST12.	BEST32.	8. Was a transcranial doppler (TCD) ever done?
24	p1f10q08_dtdys	Num	8	BEST12.	BEST32.	8. Date of Most Recent TCD
25	p1f10q08b	Num	8	BEST12.	BEST32.	8b. What was the result/diagnosis of the TCD?
26	p1f10q09	Num	8	BEST12.	BEST32.	9. Was imaging of the spleen ever done?
27	p1f10q09_dtdys	Num	8	BEST12.	BEST32.	9. Date of Most Recent imaging of the spleen
28	p1f10q09b	Num	8	BEST12.	BEST32.	9b. What type of imaging was done?
29	p1f10q09c	Num	8	BEST12.	BEST32.	9c. What was the result/diagnosis of the imaging of the spleen?
30	p1f10q10	Num	8	BEST12.	BEST32.	10. Was a pulmonary function test (PFT) ever done?
31	p1f10q10_dtdys	Num	8	BEST12.	BEST32.	10. Date of Most Recent PFT
32	p1f10q10b	Num	8	BEST12.	BEST32.	10b. What was the result/diagnosis of the PFT?

Data Set Name: scdicii_ptregistration.sas7bdat

Num	Variable	Type	Len	Format	Informat	Label
1	newid	Char	8	\$8.	\$8.	Subject ID
2	site	Num	8	BEST12.	BEST32.	Site
3	p1f6q01dys	Num	8	BEST12.	BEST32.	Date SCDIC II Registry consent (days from earliest consent)
4	p1f6q02dys	Num	8	BEST12.	BEST32.	Date of birth (days from earliest consent)
5	p1f6q04	Num	8	BEST12.	BEST32.	4. Ethnicity (check one)
6	p1f6q05	Num	8	BEST12.	BEST32.	5. Sex
7	p1f6q03___1	Num	8	BEST12.	BEST32.	Race =American Indian or Alaska Native)
8	p1f6q03___2	Num	8	BEST12.	BEST32.	Race =Asian
9	p1f6q03___3	Num	8	BEST12.	BEST32.	Race =Black or African American
10	p1f6q03___4	Num	8	BEST12.	BEST32.	Race =Native Hawaiian or Pacific Islander
11	p1f6q03___5	Num	8	BEST12.	BEST32.	Race =White
12	p1f6q03___6	Num	8	BEST12.	BEST32.	Race =Other
13	p1f6q03___7	Num	8	BEST12.	BEST32.	Race =Not Available

Data Set Name: scdicii_ptsurvey_yr1.sas7bdat

Num	Variable	Type	Len	Format	Informat	Label
1	newid	Char	8	\$8.	\$8.	Subject ID
2	site	Num	8	BEST12.	BEST32.	Site
3	p3flq00_v3v4	Num	8	BEST12.	BEST32.	What is today s date (days from reference date)
4	p3fl_opt_out_v3v4__1	Num	8	BEST12.	BEST32.	The patient has opted out of taking this survey (choice=)
5	p3flq01a	Num	8	BEST12.	BEST32.	1a. What is your year of birth?
6	p3flq02a	Num	8	BEST12.	BEST32.	2a. How old are you today?
7	p3flq05a	Num	8	BEST12.	BEST32.	5a. What is your current marital status?
8	p3flq06a	Num	8	BEST12.	BEST32.	6a. What is your approximate yearly household income? Include income from all sources.
9	p3flq07a	Num	8	BEST12.	BEST32.	7a. What is the highest grade or level of school you have completed or the highest degree you have received?
10	p3flq08a	Num	8	BEST12.	BEST32.	8a. We would like to know about what you do -- are you working, looking for work, retired, keeping house, or what?
11	p3flq09a	Num	8	BEST12.	BEST32.	9a. How old were you when you were diagnosed with sickle cell disease?
12	p3flq10a	Num	8	BEST12.	BEST32.	10a. What type of healthcare professional has been providing the majority of care for your sickle cell disease in the past 2 years?
13	p3flq01_v3v4	Num	8	BEST12.	BEST32.	1. Do you take pain medicine every day for your sickle cell disease?
14	p3flq03_v3v4	Num	8	BEST12.	BEST32.	2. In the past 12 months, how many sickle cell pain attacks (crises) did you have?
15	p3flq04_v3v4	Num	8	BEST12.	BEST32.	3. When was your last pain attack (crisis)?
16	p3flq05_v3v4	Num	8	BEST12.	BEST32.	4. How severe was your pain during your last pain attack (crisis)? Select a number from 0 to 10 below, where 0 is no pain and 10 is the worst pain imaginable.
17	p3flq06_v3v4	Num	8	BEST12.	BEST32.	5. How much did your last pain attack (crisis) interfere with your life?
18	p3flq07_v3v4	Num	8	BEST12.	BEST32.	6. About how long did your most recent pain attack (crisis) last?
19	p3flq10a_v3v4	Num	8	BEST12.	BEST32.	7a. Think about how your pain felt in the past 7 days, did your pain feel like pins and needles?
20	p3flq10b_v3v4	Num	8	BEST12.	BEST32.	7b. Think about how your pain felt in the past 7 days, did your pain feel sore?
21	p3flq09a2_v3v4	Num	8	BEST12.	BEST32.	8a. Think about how your pain felt in the past 7 days, how much did pain interfere with your day to day activities?
22	p3flq09b2_v3v4	Num	8	BEST12.	BEST32.	8b. Think about how your pain felt in the past 7 days, how much did pain interfere with work around the home?
23	p3flq09c2_v3v4	Num	8	BEST12.	BEST32.	8c. Think about how your pain felt in the past 7 days, how much did pain interfere with your ability to participate in social activities?
24	pflq09d2_v3v4	Num	8	BEST12.	BEST32.	8d. Think about how your pain felt in the past 7 days, how much did pain interfere with your household chores?
25	p3flq08a_v3v4	Num	8	BEST12.	BEST32.	9a. Think about how your pain felt in the past 7 days, how often did you have very severe pain?

Num	Variable	Type	Len	Format	Informat	Label
26	p3flq08b_v3v4	Num	8	BEST12.	BEST32.	9b. Think about how your pain felt in the past 7 days, how often did you have pain so bad that it was hard to finish what you were doing?
27	p3flq09a_v3v4	Num	8	BEST12.	BEST32.	10a. Think about how your pain felt in the past 6 months, how often did you have very severe pain?
28	p3flq09b_v3v4	Num	8	BEST12.	BEST32.	10b. Think about how your pain felt in the past 6 months,, how often did you have pain so bad that it was hard to finish what you were doing?
29	p3flq12_2_v3v4	Num	8	BEST12.	BEST32.	11. Have you had at least 15 days per month with pain for at least 6 months?
30	p3flq11_v3v4	Num	8	BEST12.	BEST32.	12. Would you say that your pain management plan is ...
31	p3flq12_v3v4	Num	8	BEST12.	BEST32.	13. Do you get regular blood transfusions for your sickle cell disease?
32	p3flq13_v3v4	Num	8	BEST12.	BEST32.	14. In the past 12 months, how many units (pints) of blood have you received?
33	p3flq14_v3v4	Num	8	BEST12.	BEST32.	15. Are you currently on iron chelation treatment (e.g., Desferal, Exjade, Jadenu, deferasirox, Ferriprox, deferiprone, phlebotomy?)
34	p3flq17b_v3v4	Num	8	BEST12.	BEST32.	16. In the past 12 months, has your spleen been removed?
35	p3flq18b_v3v4	Num	8	BEST12.	BEST32.	17. In the past 12 months, have you received an influenza (seasonal flu) vaccine?
36	p3flq16a_v3v4	Num	8	BEST12.	BEST32.	a. Has a doctor or nurse ever told you that you have lung problems such as pneumonia or acute chest syndrome
37	p3flq16b_v3v4	Num	8	BEST12.	BEST32.	b. Has a doctor or nurse ever told you that you have kidney damage
38	p3flq16c_v3v4	Num	8	BEST12.	BEST32.	c. Has a doctor or nurse ever told you that you have eye damage called retinopathy
39	p3flq16d_v3v4	Num	8	BEST12.	BEST32.	d. Has a doctor or nurse ever told you that you have damage to your hip or shoulder due to sickle cell disease
40	p3flq16e_v3v4	Num	8	BEST12.	BEST32.	e. Has a doctor or nurse ever told you that you have high blood pressure in your lungs (also called pulmonary hypertension)
41	p3flq16f_v3v4	Num	8	BEST12.	BEST32.	f. heart failure
42	p3flq16g_v3v4	Num	8	BEST12.	BEST32.	g. Has a doctor or nurse ever told you that you have blood clots in your legs or arms or that went to your lung
43	p3flq16h_v3v4	Num	8	BEST12.	BEST32.	h. Has a doctor or nurse ever told you that you have a stroke
44	p3flq16i_v3v4	Num	8	BEST12.	BEST32.	i. Has a doctor or nurse ever told you that you have asthma
45	p3flq16j_v3v4	Num	8	BEST12.	BEST32.	j. Has a doctor or nurse ever told you that you have diabetes
46	p3flq16k_v3v4	Num	8	BEST12.	BEST32.	k. Has a doctor or nurse ever told you that you have liver problems such as hepatitis, iron overload, or cirrhosis
47	p3flq16l_v3v4	Num	8	BEST12.	BEST32.	l. Has a doctor or nurse ever told you that you have skin ulcers
48	p3flq16m_v3v4	Num	8	BEST12.	BEST32.	m. Has a doctor or nurse ever told you that you have cancer or myelodysplastic syndrome (MDS)
49	p3flq16n_v3v4	Num	8	BEST12.	BEST32.	n. Has a doctor or nurse ever told you that you have positive COVID test, with or without symptoms
50	p3flq16o_v3v4	Num	8	BEST12.	BEST32.	o. Has a doctor or nurse ever told you that you have chronic or ongoing COVID symptoms (also known as long COVID or PASC)
51	p3flq19b_v3v4	Num	8	BEST12.	BEST32.	19. Have you ever received a COVID vaccine?
52	p3flq21b_v3v4	Num	8	BEST12.	BEST32.	20. Have you ever received a COVID vaccine booster shot?

Num	Variable	Type	Len	Format	Informat	Label
53	p3flq23b_v3v4	Num	8	BEST12.	BEST32.	21. Have you ever been hospitalized because of COVID?
54	p3flq26	Num	8	BEST12.	BEST32.	22. Did a doctor ever suggest you take hydroxyurea?
55	p3flq27__1	Num	8	BEST12.	BEST32.	23. What makes it difficult for you to take hydroxyurea, or is there a reason why you do not take hydroxyurea? I have no difficulties or concerns using hydroxyurea
56	p3flq27__2	Num	8	BEST12.	BEST32.	23. What makes it difficult for you to take hydroxyurea, or is there a reason why you do not take hydroxyurea? I dont know enough about the medicine
57	p3flq27__3	Num	8	BEST12.	BEST32.	23. What makes it difficult for you to take hydroxyurea, or is there a reason why you do not take hydroxyurea? Sometimes I forget to take the medicine
58	p3flq27__4	Num	8	BEST12.	BEST32.	23. What makes it difficult for you to take hydroxyurea, or is there a reason why you do not take hydroxyurea? I am worried about side effects
59	p3flq27__5	Num	8	BEST12.	BEST32.	23. What makes it difficult for you to take hydroxyurea, or is there a reason why you do not take hydroxyurea? I dont like the frequent blood tests or clinic visits
60	p3flq27__6	Num	8	BEST12.	BEST32.	23. What makes it difficult for you to take hydroxyurea, or is there a reason why you do not take hydroxyurea? Im feeling well and I dont think I need it
61	p3flq27__7	Num	8	BEST12.	BEST32.	23. What makes it difficult for you to take hydroxyurea, or is there a reason why you do not take hydroxyurea? The cost is more than I can afford
62	p3flq27__8	Num	8	BEST12.	BEST32.	23. What makes it difficult for you to take hydroxyurea, or is there a reason why you do not take hydroxyurea? I have heard that hydroxyurea may cause cancer
63	p3flq27__9	Num	8	BEST12.	BEST32.	23. What makes it difficult for you to take hydroxyurea, or is there a reason why you do not take hydroxyurea? I have heard that hydroxyurea may cause problems with having healthy children
64	p3flq27__10	Num	8	BEST12.	BEST32.	23. What makes it difficult for you to take hydroxyurea, or is there a reason why you do not take hydroxyurea? Other difficulty
65	p3flq17_v3v4	Num	8	BEST12.	BEST32.	24. Have you ever taken hydroxyurea?
66	p3flq29__1	Num	8	BEST12.	BEST32.	25. What side effects have you experienced while you were taking hydroxyurea? Hair loss/thinning
67	p3flq29__2	Num	8	BEST12.	BEST32.	25. What side effects have you experienced while you were taking hydroxyurea? Nail blackening or discoloration
68	p3flq29__3	Num	8	BEST12.	BEST32.	25. What side effects have you experienced while you were taking hydroxyurea? Lowered blood counts (e.g., platelets, white count, hemoglobin
69	p3flq29__4	Num	8	BEST12.	BEST32.	25. What side effects have you experienced while you were taking hydroxyurea? Low sperm count or other fertility problems
70	p3flq29__5	Num	8	BEST12.	BEST32.	25. What side effects have you experienced while you were taking hydroxyurea? Nausea/vomiting
71	p3flq29__6	Num	8	BEST12.	BEST32.	25. What side effects have you experienced while you were taking hydroxyurea? Skin ulcers
72	p3flq29__7	Num	8	BEST12.	BEST32.	25. What side effects have you experienced while you were taking hydroxyurea? Weight gain
73	p3flq29__8	Num	8	BEST12.	BEST32.	25. What side effects have you experienced while you were taking hydroxyurea? Headaches or dizziness

Num	Variable	Type	Len	Format	Informat	Label
74	p3flq29__9	Num	8	BEST12.	BEST32.	25. What side effects have you experienced while you were taking hydroxyurea? Fatigue/drowsiness
75	p3flq29__10	Num	8	BEST12.	BEST32.	25. What side effects have you experienced while you were taking hydroxyurea? Other
76	p3flq29__11	Num	8	BEST12.	BEST32.	25. What side effects have you experienced while you were taking hydroxyurea? No side effects
77	p3flq18_v3v4	Num	8	BEST12.	BEST32.	26. Are you currently taking hydroxyurea?
78	p3flq19_v3v4	Num	8	BEST12.	BEST32.	27. What is the reason you stopped taking hydroxyurea?
79	p3flq20_v3v4	Num	8	BEST12.	BEST32.	28. How many days did you take hydroxyurea in the PAST WEEK?
80	p3flq21_v3v4__1	Num	8	BEST12.	BEST32.	29. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Hair loss/thinning
81	p3flq21_v3v4__2	Num	8	BEST12.	BEST32.	29. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Nail blackening or discoloration
82	p3flq21_v3v4__3	Num	8	BEST12.	BEST32.	29. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Lowered blood counts (e.g., platelets, white count, hemoglobin
83	p3flq21_v3v4__4	Num	8	BEST12.	BEST32.	29. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Low sperm count or other fertility problems
84	p3flq21_v3v4__5	Num	8	BEST12.	BEST32.	29. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Nausea/vomiting
85	p3flq21_v3v4__6	Num	8	BEST12.	BEST32.	29. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Skin ulcers
86	p3flq21_v3v4__7	Num	8	BEST12.	BEST32.	29. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Weight gain
87	p3flq21_v3v4__8	Num	8	BEST12.	BEST32.	29. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Headaches or dizziness
88	p3flq21_v3v4__9	Num	8	BEST12.	BEST32.	29. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Fatigue/drowsiness
89	p3flq21_v3v4__10	Num	8	BEST12.	BEST32.	29. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? =No side effects
90	p3flq22_v3v4__1	Num	8	BEST12.	BEST32.	30. In the last 12 months, what makes it difficult for you to take hydroxyurea, or is there a reason why you do not take hydroxyurea? I have no difficulties or concerns using hydroxyurea
91	p3flq22_v3v4__2	Num	8	BEST12.	BEST32.	30. In the last 12 months, what makes it difficult for you to take hydroxyurea, or is there a reason why you do not take hydroxyurea? I dont know enough about the medicine
92	p3flq22_v3v4__3	Num	8	BEST12.	BEST32.	30. In the last 12 months, what makes it difficult for you to take hydroxyurea, or is there a reason why you do not take hydroxyurea? Sometimes I forget to take the medicine
93	p3flq22_v3v4__4	Num	8	BEST12.	BEST32.	30. In the last 12 months, what makes it difficult for you to take hydroxyurea, or is there a reason why you do not take hydroxyurea? I am worried about side effects

Num	Variable	Type	Len	Format	Informat	Label
94	p3flq22_v3v4__5	Num	8	BEST12.	BEST32.	30. In the last 12 months, what makes it difficult for you to take hydroxyurea, or is there a reason why you do not take hydroxyurea? I dont like the frequent blood tests or clinic visits
95	p3flq22_v3v4__6	Num	8	BEST12.	BEST32.	30. In the last 12 months, what makes it difficult for you to take hydroxyurea, or is there a reason why you do not take hydroxyurea? Im feeling well and I dont think I need it
96	p3flq22_v3v4__7	Num	8	BEST12.	BEST32.	30. In the last 12 months, what makes it difficult for you to take hydroxyurea, or is there a reason why you do not take hydroxyurea? The cost is more than I can afford
97	p3flq22_v3v4__8	Num	8	BEST12.	BEST32.	30. In the last 12 months, what makes it difficult for you to take hydroxyurea, or is there a reason why you do not take hydroxyurea? I have heard that hydroxyurea may cause cancer
98	p3flq22_v3v4__9	Num	8	BEST12.	BEST32.	30. In the last 12 months, what makes it difficult for you to take hydroxyurea, or is there a reason why you do not take hydroxyurea? I have heard that hydroxyurea may cause problems with having healthy children
99	p3flq22_v3v4__97	Num	8	BEST12.	BEST32.	30. In the last 12 months, what makes it difficult for you to take hydroxyurea, or is there a reason why you do not take hydroxyurea? Other difficulty
100	p3flq23_v3v4	Num	8	BEST12.	BEST32.	31. In the past 12 months, have you taken the drug called Endari (l-glutamine)?
101	p3flq24_v3v4	Num	8	BEST12.	BEST32.	32. Are you currently taking Endari?
102	p3flq25_v3v4	Num	8	BEST12.	BEST32.	33. In the past 12 months, what is the reason you discontinued or stopped taking Endari? Please select one from the list below.
103	p3flq26_v3v4	Num	8	BEST12.	BEST32.	34. How many days did you take Endari in the PAST WEEK?
104	p3flq27_v3v4__1	Num	8	BEST12.	BEST32.	35. In the last 12 months, what side effects have you experienced while you were taking Endari? No side effects
105	p3flq27_v3v4__2	Num	8	BEST12.	BEST32.	35. In the last 12 months, what side effects have you experienced while you were taking Endari? Nausea/vomiting
106	p3flq27_v3v4__3	Num	8	BEST12.	BEST32.	35. In the last 12 months, what side effects have you experienced while you were taking Endari? Stomach pain
107	p3flq27_v3v4__4	Num	8	BEST12.	BEST32.	35. In the last 12 months, what side effects have you experienced while you were taking Endari? Cough
108	p3flq27_v3v4__5	Num	8	BEST12.	BEST32.	35. In the last 12 months, what side effects have you experienced while you were taking Endari? Headaches or dizziness
109	p3flq27_v3v4__6	Num	8	BEST12.	BEST32.	35. In the last 12 months, what side effects have you experienced while you were taking Endari? Other not listed above
110	p3flq30_v4	Num	8	BEST12.	BEST32.	36. In the past 12 months, have you taken the drug called Adakveo (crizanlizumab)?
111	p3flq31_v4	Num	8	BEST12.	BEST32.	37. Are you currently taking Adakveo?
112	p3flq32_v4	Num	8	BEST12.	BEST32.	38. In the past 12 months, what is the reason you discontinued or stopped taking Adakveo? Please select one from the list below.
113	p3flq33_v4	Num	8	BEST12.	BEST32.	39. How many infusions of Adakveo have you missed or rescheduled in the PAST 6 MONTHS?
114	p3flq34_v4__1	Num	8	BEST12.	BEST32.	40. In the last 12 months, what side effects have you experienced while you were taking Adakveo? No side effects
115	p3flq34_v4__2	Num	8	BEST12.	BEST32.	40. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Fever

Num	Variable	Type	Len	Format	Informat	Label
116	p3flq34_v4__3	Num	8	BEST12.	BEST32.	40. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Chills or shivering
117	p3flq34_v4__4	Num	8	BEST12.	BEST32.	40. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Nausea
118	p3flq34_v4__5	Num	8	BEST12.	BEST32.	40. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Vomiting
119	p3flq34_v4__6	Num	8	BEST12.	BEST32.	40. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Shortness of breath
120	p3flq34_v4__7	Num	8	BEST12.	BEST32.	40. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Muscle aches (myalias
121	p3flq34_v4__8	Num	8	BEST12.	BEST32.	40. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Other not listed above
122	p3flq35_v4	Num	8	BEST12.	BEST32.	41. In the past 12 months, have you taken the drug called Oxbryta (voxelotor)?
123	p3flq36_v4	Num	8	BEST12.	BEST32.	42. Are you currently taking Oxbryta?
124	p3flq37_v4	Num	8	BEST12.	BEST32.	43. In the past 12 months, what is the reason you discontinued or stopped taking Oxbryta? Please select one from the list below.
125	p3flq38_v4	Num	8	BEST12.	BEST32.	44. How many days did you take Oxbryta in the PAST WEEK?
126	p3flq39_v4__1	Num	8	BEST12.	BEST32.	45. In the last 12 months, what side effects have you experienced while you were taking Oxbryta? No side effects
127	p3flq39_v4__2	Num	8	BEST12.	BEST32.	45. In the last 12 months, what side effects have you experienced while you were taking Oxbryta? Rash or hives
128	p3flq39_v4__3	Num	8	BEST12.	BEST32.	45. In the last 12 months, what side effects have you experienced while you were taking Oxbryta? Headache
129	p3flq39_v4__4	Num	8	BEST12.	BEST32.	45. In the last 12 months, what side effects have you experienced while you were taking Oxbryta? Nausea
130	p3flq39_v4__5	Num	8	BEST12.	BEST32.	45. In the last 12 months, what side effects have you experienced while you were taking Oxbryta? Abdominal pain
131	p3flq39_v4__6	Num	8	BEST12.	BEST32.	45. In the last 12 months, what side effects have you experienced while you were taking Oxbryta? Loose stools
132	p3flq39_v4__7	Num	8	BEST12.	BEST32.	45. In the last 12 months, what side effects have you experienced while you were taking Oxbryta? Other not listed above
133	p3flq42_v3v4	Num	8	BEST12.	BEST32.	47. How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?
134	p3flq53a_v3v4	Num	8	BEST12.	BEST32.	a. Current Level of Confidence: I can follow directions when my doctor changes my medications.
135	p3flq53b_v3v4	Num	8	BEST12.	BEST32.	b. Current Level of Confidence: I can take my medication when there is a change in my usual day (unexpected things happen).
136	p3flq53c_v3v4	Num	8	BEST12.	BEST32.	c. Current Level of Confidence: I can manage my medication without help.
137	p3flq54a_v3v4	Num	8	BEST12.	BEST32.	d. Current Level of Confidence: I can list my medications, including the doses and schedule.
138	p3flq54b_v3v4	Num	8	BEST12.	BEST32.	a. In general, would you say your quality of life is...
139	p3flq53d_v3v4	Num	8	BEST12.	BEST32.	b. In general, how would you rate your mental health, including your mood and your ability to think?

Num	Variable	Type	Len	Format	Informat	Label
140	p3flq33a_v3v4	Num	8	BEST12.	BEST32.	a. I have someone who will listen to me when I need to talk
141	p3flq33b_v3v4	Num	8	BEST12.	BEST32.	b. I have someone to confide in or talk to about myself or my problems
142	p3flq33c_v3v4	Num	8	BEST12.	BEST32.	c. I have someone who makes me feel appreciated
143	p3flq33d_v3v4	Num	8	BEST12.	BEST32.	d. I have someone to talk with when I have a bad day
144	p3flq34a_v3v4	Num	8	BEST12.	BEST32.	a. Think about how you felt in the past 7 days, I felt worthless.
145	p3flq34b_v3v4	Num	8	BEST12.	BEST32.	b. Think about how you felt in the past 7 days, I felt helpless.
146	p3flq34c_v3v4	Num	8	BEST12.	BEST32.	c. Think about how you felt in the past 7 days, I felt depressed.
147	p3flq34d_v3v4	Num	8	BEST12.	BEST32.	d. Think about how you felt in the past 7 days, I felt hopeless.
148	p3flq34e_v3v4	Num	8	BEST12.	BEST32.	e. Think about how you felt in the past 7 days, How often did you feel completely hopeless because of your health?
149	p3flq34f_v3v4	Num	8	BEST12.	BEST32.	f. Think about how you felt in the past 7 days, How often were you very worried about needing to go to the hospital?
150	p3flq57a_v3v4	Num	8	BEST12.	BEST32.	a. In the past 7 days, I feel fatigued.
151	p3flq57b_v3v4	Num	8	BEST12.	BEST32.	b. In the past 7 days, I have trouble starting things because I am tired.
152	p3flq57c_v3v4	Num	8	BEST12.	BEST32.	c. In the past 7 days, How run-down did you feel on average?
153	p3flq57d_v3v4	Num	8	BEST12.	BEST32.	d. In the past 7 days, How fatigued were you on average?
154	p3flq48e_v3v4	Num	8	BEST12.	BEST32.	e. In the past 7 days, I felt tired.
155	p3flq35a_v3v4	Num	8	BEST12.	BEST32.	a. In the past 7 days, I felt fearful
156	p3flq35b_v3v4	Num	8	BEST12.	BEST32.	b. In the past 7 days, I found it hard to focus on anything other than my anxiety
157	p3flq35c_v3v4	Num	8	BEST12.	BEST32.	c. In the past 7 days, my worries overwhelmed me
158	p3flq35d_v3v4	Num	8	BEST12.	BEST32.	d. In the past 7 days, I felt uneasy
159	p3flq36a_v3v4	Num	8	BEST12.	BEST32.	a. In the past 7 days, I had to read something several times to understand it.
160	p3flq36b_v3v4	Num	8	BEST12.	BEST32.	b. In the past 7 days, my thinking was slow.
161	p3flq36c_v3v4	Num	8	BEST12.	BEST32.	c. In the past 7 days, I had to work really hard to pay attention or I would make a mistake.
162	p3flq36d_v3v4	Num	8	BEST12.	BEST32.	d. In the past 7 days, I had trouble concentrating.
163	p3flq37a_v3v4	Num	8	BEST12.	BEST32.	a. How much difficulty do you currently have reading and following complex instructions (e.g., directions for a new medication)?
164	p3flq37b_v3v4	Num	8	BEST12.	BEST32.	b. How much difficulty do you currently have planning for and keeping appointments that are not part of your weekly routine (e.g., therapy or doctor appointment, social gathering with friends/family)?
165	p3flq37c_v3v4	Num	8	BEST12.	BEST32.	c. How much difficulty do you currently have managing your time to do most of your daily activities?
166	p3flq37d_v3v4	Num	8	BEST12.	BEST32.	d. How much difficulty do you currently have learning new tasks or instructions?
167	p3flq38a_v3v4	Num	8	BEST12.	BEST32.	a. In the past 30 days, how much did you rely on others to take care of you because of your health?
168	p3flq38b_v3v4	Num	8	BEST12.	BEST32.	b. In the past 30 days, how much did your health make it hard for you to do things with your friends?

Num	Variable	Type	Len	Format	Informat	Label
169	p3flq38c_v3v4	Num	8	BEST12.	BEST32.	c. In the past 30 days, how often did your health slow you down?
170	p3flq38d_v3v4	Num	8	BEST12.	BEST32.	d. In the past 30 days, how often did your health make it hard for you to do things?
171	p3flq38e_v3v4	Num	8	BEST12.	BEST32.	e. In the past 30 days, how often did your health keep you from going out?
172	p3flq39a_v3v4	Num	8	BEST12.	BEST32.	a. In the past month, I feel alone and apart from others
173	p3flq39b_v3v4	Num	8	BEST12.	BEST32.	b. In the past month, I feel left out
174	p3flq39c_v3v4	Num	8	BEST12.	BEST32.	c. In the past month, I feel that I am no longer close to anyone
175	p3flq39d_v3v4	Num	8	BEST12.	BEST32.	d. In the past month, I feel alone
176	p3flq39e_v3v4	Num	8	BEST12.	BEST32.	e. In the past month, I feel lonely
177	p3flq39f_v3v4	Num	8	BEST12.	BEST32.	f. In the past month, I feel isolated from others
178	p3flq40a_v3v4	Num	8	BEST12.	BEST32.	a. I tend to bounce back quickly after hard times
179	p3flq40b_v3v4	Num	8	BEST12.	BEST32.	b. I have a hard time making it through stressful events
180	p3flq40c_v3v4	Num	8	BEST12.	BEST32.	c. It does not take me long to recover from a stressful event
181	p3flq40d_v3v4	Num	8	BEST12.	BEST32.	d. It is hard for me to snap back when something bad happens
182	p3flq40e_v3v4	Num	8	BEST12.	BEST32.	e. I usually come through difficult times with little trouble
183	p3flq40f_v3v4	Num	8	BEST12.	BEST32.	f. I tend to take a long time to get over set-backs in my life
184	p3flq41_1a_v3v4	Num	8	BEST12.	BEST32.	a. In general, would you say your health is
185	p3flq41_1b_v3v4	Num	8	BEST12.	BEST32.	b. In general, how would you rate your physical health?
186	p3flq41_2b_v3v4	Num	8	BEST12.	BEST32.	c. To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?
187	p3flq65a_v3v4	Num	8	BEST12.	BEST32.	a. In the past 7 days, how often were your joints very stiff when you woke up?
188	p3flq65b_v3v4	Num	8	BEST12.	BEST32.	b. In the past 7 days, how often were your joints very stiff during the day?
189	p3flq65c_v3v4	Num	8	BEST12.	BEST32.	c. In the past 7 days, how often were your joints so stiff during the day that you could not move?
190	p3flq65d_v3v4	Num	8	BEST12.	BEST32.	d. In the past 7 days, how often did you wake up so stiff that you could not move?
191	p3flq65e_v3v4	Num	8	BEST12.	BEST32.	e. In the past 7 days, how often did it take you a very long time to get out of bed because of stiffness?
192	p3flq32a_v3v4	Num	8	BEST12.	BEST32.	a. In the past 7 days, how often did you stay up most of the night because you could not fall asleep?
193	p3flq32b_v3v4	Num	8	BEST12.	BEST32.	b. In the past 7 days, how often did you have a lot of trouble falling asleep?
194	p3flq32c_v3v4	Num	8	BEST12.	BEST32.	c. In the past 7 days, how often was it very easy for you to fall asleep?
195	p3flq32d_v3v4	Num	8	BEST12.	BEST32.	d. In the past 7 days, how often did you stay up all night because you could not fall asleep?
196	p3flq32e_v3v4	Num	8	BEST12.	BEST32.	e. In the past 7 days, how often did you stay up half of the night because you could not fall asleep?

Num	Variable	Type	Len	Format	Informat	Label
197	p3flq44_v3v4	Num	8	BEST12.	BEST32.	63. During the past 12 months, was there any time when you didn't get the medical care you needed or had delays in getting the care you needed?
198	p3flq45_v3v4__1	Num	8	BEST12.	BEST32.	64. In the past 12 months, did you not get the medical care you needed or have delays getting medical care you needed for any of the following reasons? Worry about the cost
199	p3flq45_v3v4__2	Num	8	BEST12.	BEST32.	64. In the past 12 months, did you not get the medical care you needed or have delays getting medical care you needed for any of the following reasons? The doctor or hospital wouldn't accept your health insurance
200	p3flq45_v3v4__3	Num	8	BEST12.	BEST32.	64. In the past 12 months, did you not get the medical care you needed or have delays getting medical care you needed for any of the following reasons? Your health plan wouldn't pay for the treatment
201	p3flq45_v3v4__4	Num	8	BEST12.	BEST32.	64. In the past 12 months, did you not get the medical care you needed or have delays getting medical care you needed for any of the following reasons? You couldn't get an appointment soon enough
202	p3flq45_v3v4__5	Num	8	BEST12.	BEST32.	64. In the past 12 months, did you not get the medical care you needed or have delays getting medical care you needed for any of the following reasons? You couldn't get there when the doctor's office or clinic was open
203	p3flq45_v3v4__6	Num	8	BEST12.	BEST32.	64. In the past 12 months, did you not get the medical care you needed or have delays getting medical care you needed for any of the following reasons? It takes too long to get to the doctor's office or clinic from your house or work
204	p3flq45_v3v4__7	Num	8	BEST12.	BEST32.	64. In the past 12 months, did you not get the medical care you needed or have delays getting medical care you needed for any of the following reasons? You couldn't get through on the telephone
205	p3flq45_v3v4__8	Num	8	BEST12.	BEST32.	64. In the past 12 months, did you not get the medical care you needed or have delays getting medical care you needed for any of the following reasons? You were too busy with work or other commitments to take the time
206	p3flq45_v3v4__9	Num	8	BEST12.	BEST32.	64. In the past 12 months, did you not get the medical care you needed or have delays getting medical care you needed for any of the following reasons? You didn't think the problem was serious enough
207	p3flq45_v3v4__10	Num	8	BEST12.	BEST32.	64. In the past 12 months, did you not get the medical care you needed or have delays getting medical care you needed for any of the following reasons? =You had previous bad experiences with the health care system
208	p3flq45_v3v4__11	Num	8	BEST12.	BEST32.	64. In the past 12 months, did you not get the medical care you needed or have delays getting medical care you needed for any of the following reasons? =People at the doctor's office or clinic don't speak the same language I do
209	p3flq45_v3v4__12	Num	8	BEST12.	BEST32.	64. In the past 12 months, did you not get the medical care you needed or have delays getting medical care you needed for any of the following reasons? =The Coronavirus/COVID-19 pandemic
210	p3flq45_v3v4__97	Num	8	BEST12.	BEST32.	64. In the past 12 months, did you not get the medical care you needed or have delays getting medical care you needed for any of the following reasons? =Some other reason not listed above)

Num	Variable	Type	Len	Format	Informat	Label
211	p3flq46_v3v4	Num	8	BEST12.	BEST32.	65. How hard is it for you to pay for the very basics like food, housing, medical care, and heating?
212	p3flq47_v3v4	Num	8	BEST12.	BEST32.	66. Did you lose your health insurance in the past year?
213	p3flq48_a1_v3v4	Num	8	BEST12.	BEST32.	a. Experienced discrimination because of your race, ethnicity, or color in any of these situation: At school?
214	p3flq48_a2_v3v4	Num	8	BEST12.	BEST32.	How many times did this happen in the past 12 months?
215	p3flq48_b1_v3v4	Num	8	BEST12.	BEST32.	b. Experienced discrimination because of your race, ethnicity, or color in any of these situation: Getting hired or getting a job?
216	p3flq48_b2_v3v4	Num	8	BEST12.	BEST32.	How many times did this happen in the past 12 months?
217	p3flq48_c1_v3v4	Num	8	BEST12.	BEST32.	c. Experienced discrimination because of your race, ethnicity, or color in any of these situation: At work?
218	p3flq48_c2_v3v4	Num	8	BEST12.	BEST32.	How many times did this happen in the past 12 months?
219	p3flq48_d1_v3v4	Num	8	BEST12.	BEST32.	d. Experienced discrimination because of your race, ethnicity, or color in any of these situation: Getting housing?
220	p3flq48_d2_v3v4	Num	8	BEST12.	BEST32.	How many times did this happen in the past 12 months?
221	p3flq48_e1_v3v4	Num	8	BEST12.	BEST32.	e. Experienced discrimination because of your race, ethnicity, or color in any of these situation: Getting medical care?
222	p3flq48_e2_v3v4	Num	8	BEST12.	BEST32.	How many times did this happen in the past 12 months?
223	p3flq48_f1_v3v4	Num	8	BEST12.	BEST32.	f. Experienced discrimination because of your race, ethnicity, or color in any of these situation: Getting service in a store or restaurant?
224	p3flq48_f2_v3v4	Num	8	BEST12.	BEST32.	How many times did this happen in the past 12 months?
225	p3flq48_g1_v3v4	Num	8	BEST12.	BEST32.	g. Experienced discrimination because of your race, ethnicity, or color in any of these situation: Getting credit, bank loans, or a mortgage?
226	p3flq48_g2_v3v4	Num	8	BEST12.	BEST32.	How many times did this happen in the past 12 months?
227	p3flq48_h1_v3v4	Num	8	BEST12.	BEST32.	h. Experienced discrimination because of your race, ethnicity, or color in any of these situation: On the street or in a public setting?
228	p3flq48_h2_v3v4	Num	8	BEST12.	BEST32.	How many times did this happen in the past 12 months?
229	p3flq48_i1_v3v4	Num	8	BEST12.	BEST32.	i. Experienced discrimination because of your race, ethnicity, or color in any of these situation: From the police or in the courts?
230	p3flq48_i2_v3v4	Num	8	BEST12.	BEST32.	How many times did this happen in the past 12 months?
231	p3flq72_v3v4	Num	8	BEST12.	BEST32.	68. Have you consumed at least one alcoholic drink in the past 12 months?
232	p3flq73_v3v4	Num	8	BEST12.	BEST32.	69. How often do you have a drink containing alcohol?
233	p3flq74_v3v4	Num	8	BEST12.	BEST32.	70. During the last 30 days, on how many days (if any) have you used marijuana?
234	p3flq75_v3v4	Num	8	BEST12.	BEST32.	71. Have you ever used one or more tobacco products (such as cigarettes, cigars, pipe, chewing tobacco)?
235	p3flq76_v3v4	Num	8	BEST12.	BEST32.	72. What was your age when you first started using tobacco products?
236	p3flq77_v3v4	Num	8	BEST12.	BEST32.	73. Have you used tobacco products in the past 12 months?
237	p3flq78_v3v4	Num	8	BEST12.	BEST32.	74. What was your age when you stopped using tobacco products?
238	p3flq80_v3v4	Num	8	BEST12.	BEST32.	75. In the past 30 days, what is the average number of cigarettes you smoked per day?

