

Data Set Name: *scdicregistry_femalepreg.sas7bdat*

Num	Variable	Type	Len	Label
1	p1f3q04_1	Num	8	4. What was the outcome of pregnancy #1?
2	p1f3q04_2	Num	8	4. What was the outcome of pregnancy #2?
3	p1f3q04_3	Num	8	4. What was the outcome of pregnancy #3?
4	p1f3q04_4	Num	8	4. What was the outcome of pregnancy #4?
5	p1f3q04_5	Num	8	4. What was the outcome of pregnancy #5?
6	p1f3q04_6	Num	8	4. What was the outcome of pregnancy #6?
7	p1f3q04_7	Num	8	4. What was the outcome of pregnancy #7?
8	p1f3q04_8	Num	8	4. What was the outcome of pregnancy #8?
9	p1f3q04_9	Num	8	4. What was the outcome of pregnancy #9?
10	p1f3q04_10	Num	8	4. What was the outcome of pregnancy #10?
11	p1f3q04_11	Num	8	4. What was the outcome of pregnancy #11?
12	p1f3q05_1	Num	8	5. Pregnancy #1 - taking hydroxyurea at the time of conception or within the month before conception?
13	p1f3q05_2	Num	8	5. Pregnancy #2 - taking hydroxyurea at the time of conception or within the month before conception?
14	p1f3q05_3	Num	8	5. Pregnancy #3 - taking hydroxyurea at the time of conception or within the month before conception?
15	p1f3q05_4	Num	8	5. Pregnancy #4 - taking hydroxyurea at the time of conception or within the month before conception?
16	p1f3q05_5	Num	8	5. Pregnancy #5 - taking hydroxyurea at the time of conception or within the month before conception?
17	p1f3q05_6	Num	8	5. Pregnancy #6 - taking hydroxyurea at the time of conception or within the month before conception?
18	p1f3q05_7	Num	8	5. Pregnancy #7 - taking hydroxyurea at the time of conception or within the month before conception?
19	p1f3q05_8	Num	8	5. Pregnancy #8 - taking hydroxyurea at the time of conception or within the month before conception?
20	p1f3q05_9	Num	8	5. Pregnancy #9 - taking hydroxyurea at the time of conception or within the month before conception?
21	p1f3q05_10	Num	8	5. Pregnancy #10 - taking hydroxyurea at the time of conception or within the month before conception?
22	p1f3q05_11	Num	8	5. Pregnancy #11 - taking hydroxyurea at the time of conception or within the month before conception?
23	p1f3q06_1__1	Num	8	6. During pregnancy #1 were you taking hydroxyurea? No, did not take HU
24	p1f3q06_2__1	Num	8	6. During pregnancy #2 were you taking hydroxyurea? No, did not take HU
25	p1f3q06_3__1	Num	8	6. During pregnancy #3 were you taking hydroxyurea? No, did not take HU
26	p1f3q06_4__1	Num	8	6. During pregnancy #4 were you taking hydroxyurea? No, did not take HU
27	p1f3q06_5__1	Num	8	6. During pregnancy #5 were you taking hydroxyurea? No, did not take HU
28	p1f3q06_6__1	Num	8	6. During pregnancy #6 were you taking hydroxyurea? No, did not take HU
29	p1f3q06_7__1	Num	8	6. During pregnancy #7 were you taking hydroxyurea? No, did not take HU
30	p1f3q06_8__1	Num	8	6. During pregnancy #8 were you taking hydroxyurea? No, did not take HU

Num	Variable	Type	Len	Label
31	p1f3q06_9__1	Num	8	6. During pregnancy #9 were you taking hydroxyurea? No, did not take HU
32	p1f3q06_10__1	Num	8	6. During pregnancy #10 were you taking hydroxyurea? No, did not take HU
33	p1f3q06_11__1	Num	8	6. During pregnancy #11 were you taking hydroxyurea? No, did not take HU
34	p1f3q06_1__2	Num	8	6. During pregnancy #1 were you taking hydroxyurea? Yes, during 1st trimester
35	p1f3q06_2__2	Num	8	6. During pregnancy #2 were you taking hydroxyurea? Yes, during 1st trimester
36	p1f3q06_3__2	Num	8	6. During pregnancy #3 were you taking hydroxyurea? Yes, during 1st trimester
37	p1f3q06_4__2	Num	8	6. During pregnancy #4 were you taking hydroxyurea? Yes, during 1st trimester
38	p1f3q06_5__2	Num	8	6. During pregnancy #5 were you taking hydroxyurea? Yes, during 1st trimester
39	p1f3q06_6__2	Num	8	6. During pregnancy #6 were you taking hydroxyurea? Yes, during 1st trimester
40	p1f3q06_7__2	Num	8	6. During pregnancy #7 were you taking hydroxyurea? Yes, during 1st trimester
41	p1f3q06_8__2	Num	8	6. During pregnancy #8 were you taking hydroxyurea? Yes, during 1st trimester
42	p1f3q06_9__2	Num	8	6. During pregnancy #9 were you taking hydroxyurea? Yes, during 1st trimester
43	p1f3q06_10__2	Num	8	6. During pregnancy #10 were you taking hydroxyurea? Yes, during 1st trimester
44	p1f3q06_11__2	Num	8	6. During pregnancy #11 were you taking hydroxyurea? Yes, during 1st trimester
45	p1f3q06_1__3	Num	8	6. During pregnancy #1 were you taking hydroxyurea? Yes, during 2nd trimester
46	p1f3q06_2__3	Num	8	6. During pregnancy #2 were you taking hydroxyurea? Yes, during 2nd trimester
47	p1f3q06_3__3	Num	8	6. During pregnancy #3 were you taking hydroxyurea? Yes, during 2nd trimester
48	p1f3q06_4__3	Num	8	6. During pregnancy #4 were you taking hydroxyurea? Yes, during 2nd trimester
49	p1f3q06_5__3	Num	8	6. During pregnancy #5 were you taking hydroxyurea? Yes, during 2nd trimester
50	p1f3q06_6__3	Num	8	6. During pregnancy #6 were you taking hydroxyurea? Yes, during 2nd trimester
51	p1f3q06_7__3	Num	8	6. During pregnancy #7 were you taking hydroxyurea? Yes, during 2nd trimester
52	p1f3q06_8__3	Num	8	6. During pregnancy #8 were you taking hydroxyurea? Yes, during 2nd trimester
53	p1f3q06_9__3	Num	8	6. During pregnancy #9 were you taking hydroxyurea? Yes, during 2nd trimester
54	p1f3q06_10__3	Num	8	6. During pregnancy #10 were you taking hydroxyurea? Yes, during 2nd trimester
55	p1f3q06_11__3	Num	8	6. During pregnancy #11 were you taking hydroxyurea? Yes, during 2nd trimester
56	p1f3q06_1__4	Num	8	6. During pregnancy #1 were you taking hydroxyurea? Yes, during 3rd trimester
57	p1f3q06_2__4	Num	8	6. During pregnancy #2 were you taking hydroxyurea? Yes, during 3rd trimester
58	p1f3q06_3__4	Num	8	6. During pregnancy #3 were you taking hydroxyurea? Yes, during 3rd trimester
59	p1f3q06_4__4	Num	8	6. During pregnancy #4 were you taking hydroxyurea? Yes, during 3rd trimester
60	p1f3q06_5__4	Num	8	6. During pregnancy #5 were you taking hydroxyurea? Yes, during 3rd trimester
61	p1f3q06_6__4	Num	8	6. During pregnancy #6 were you taking hydroxyurea? Yes, during 3rd trimester
62	p1f3q06_7__4	Num	8	6. During pregnancy #7 were you taking hydroxyurea? Yes, during 3rd trimester
63	p1f3q06_8__4	Num	8	6. During pregnancy #8 were you taking hydroxyurea? Yes, during 3rd trimester
64	p1f3q06_9__4	Num	8	6. During pregnancy #9 were you taking hydroxyurea? Yes, during 3rd trimester
65	p1f3q06_10__4	Num	8	6. During pregnancy #10 were you taking hydroxyurea? Yes, during 3rd trimester
66	p1f3q06_11__4	Num	8	6. During pregnancy #11 were you taking hydroxyurea? Yes, during 3rd trimester
67	p1f3q06_1__99	Num	8	6. During pregnancy #1 were you taking hydroxyurea? Dont remember
68	p1f3q06_2__99	Num	8	6. During pregnancy #2 were you taking hydroxyurea? Dont remember
69	p1f3q06_3__99	Num	8	6. During pregnancy #3 were you taking hydroxyurea? Dont remember

Num	Variable	Type	Len	Label
70	p1f3q06_4__99	Num	8	6. During pregnancy #4 were you taking hydroxyurea? Dont remember
71	p1f3q06_5__99	Num	8	6. During pregnancy #5 were you taking hydroxyurea? Dont remember
72	p1f3q06_6__99	Num	8	6. During pregnancy #6 were you taking hydroxyurea? Dont remember
73	p1f3q06_7__99	Num	8	6. During pregnancy #7 were you taking hydroxyurea? Dont remember
74	p1f3q06_8__99	Num	8	6. During pregnancy #8 were you taking hydroxyurea? Dont remember
75	p1f3q06_9__99	Num	8	6. During pregnancy #9 were you taking hydroxyurea? Dont remember
76	p1f3q06_10__99	Num	8	6. During pregnancy #10 were you taking hydroxyurea? Dont remember
77	p1f3q06_11__99	Num	8	6. During pregnancy #11 were you taking hydroxyurea? Dont remember
78	p1f3q07_1	Num	8	7. Did you take any fertility drugs or receive any procedure from a health care worker to help you get pregnant with pregnancy #1?
79	p1f3q07_2	Num	8	7. Did you take any fertility drugs or receive any procedure from a health care worker to help you get pregnant with pregnancy #2?
80	p1f3q07_3	Num	8	7. Did you take any fertility drugs or receive any procedure from a health care worker to help you get pregnant with pregnancy #3?
81	p1f3q07_4	Num	8	7. Did you take any fertility drugs or receive any procedure from a health care worker to help you get pregnant with pregnancy #4?
82	p1f3q07_5	Num	8	7. Did you take any fertility drugs or receive any procedure from a health care worker to help you get pregnant with pregnancy #5?
83	p1f3q07_6	Num	8	7. Did you take any fertility drugs or receive any procedure from a health care worker to help you get pregnant with pregnancy #6?
84	p1f3q07_7	Num	8	7. Did you take any fertility drugs or receive any procedure from a health care worker to help you get pregnant with pregnancy #7?
85	p1f3q07_8	Num	8	7. Did you take any fertility drugs or receive any procedure from a health care worker to help you get pregnant with pregnancy #8?
86	p1f3q07_9	Num	8	7. Did you take any fertility drugs or receive any procedure from a health care worker to help you get pregnant with pregnancy #9?
87	p1f3q07_10	Num	8	7. Did you take any fertility drugs or receive any procedure from a health care worker to help you get pregnant with pregnancy #10?
88	p1f3q07_11	Num	8	7. Did you take any fertility drugs or receive any procedure from a health care worker to help you get pregnant with pregnancy #11?
89	p1f3q08_1	Num	8	8. How many babies were born with pregnancy #1?
90	p1f3q08_2	Num	8	8. How many babies were born with pregnancy #2?
91	p1f3q08_3	Num	8	8. How many babies were born with pregnancy #3?
92	p1f3q08_4	Num	8	8. How many babies were born with pregnancy #4?
93	p1f3q08_5	Num	8	8. How many babies were born with pregnancy #5?
94	p1f3q08_6	Num	8	8. How many babies were born with pregnancy #6?
95	p1f3q08_7	Num	8	8. How many babies were born with pregnancy #7?
96	p1f3q08_8	Num	8	8. How many babies were born with pregnancy #8?
97	p1f3q08_9	Num	8	8. How many babies were born with pregnancy #9?
98	p1f3q08_10	Num	8	8. How many babies were born with pregnancy #10?
99	p1f3q08_11	Num	8	8. How many babies were born with pregnancy #11?
100	p1f3q09_1	Num	8	9. Pregnancy #1 -Was the baby (or babies) born prematurely?
101	p1f3q09_2	Num	8	9. Pregnancy #2 -Was the baby (or babies) born prematurely?

Num	Variable	Type	Len	Label
102	p1f3q09_3	Num	8	9. Pregnancy #3 -Was the baby (or babies) born prematurely?
103	p1f3q09_4	Num	8	9. Pregnancy #4 -Was the baby (or babies) born prematurely?
104	p1f3q09_5	Num	8	9. Pregnancy #5 -Was the baby (or babies) born prematurely?
105	p1f3q09_6	Num	8	9. Pregnancy #6 -Was the baby (or babies) born prematurely?
106	p1f3q09_7	Num	8	9. Pregnancy #7 -Was the baby (or babies) born prematurely?
107	p1f3q09_8	Num	8	9. Pregnancy #8 -Was the baby (or babies) born prematurely?
108	p1f3q09_9	Num	8	9. Pregnancy #9 -Was the baby (or babies) born prematurely?
109	p1f3q09_10	Num	8	9. Pregnancy #10 -Was the baby (or babies) born prematurely?
110	p1f3q09_11	Num	8	9. Pregnancy #11 -Was the baby (or babies) born prematurely?
111	p1f3q09a_1r	Num	8	9. Pregnancy #1 -if born prematurely, how many weeks of gestation
112	p1f3q09a_2r	Num	8	9. Pregnancy #2 -if born prematurely, how many weeks of gestation
113	p1f3q09a_3r	Num	8	9. Pregnancy #3 -if born prematurely, how many weeks of gestation
114	p1f3q09a_4r	Num	8	9. Pregnancy #4 -if born prematurely, how many weeks of gestation
115	p1f3q09a_5r	Num	8	9. Pregnancy #5 -if born prematurely, how many weeks of gestation
116	p1f3q09a_6r	Num	8	9. Pregnancy #6 -if born prematurely, how many weeks of gestation
117	p1f3q09a_7r	Num	8	9. Pregnancy #7 -if born prematurely, how many weeks of gestation
118	p1f3q09a_8r	Num	8	9. Pregnancy #8 -if born prematurely, how many weeks of gestation
119	p1f3q09a_9r	Num	8	9. Pregnancy #9 -if born prematurely, how many weeks of gestation
120	p1f3q09a_10r	Num	8	9. Pregnancy #10 -if born prematurely, how many weeks of gestation
121	p1f3q09a_11r	Num	8	9. Pregnancy #11 -if born prematurely, how many weeks of gestation
122	p1f3q10_1	Num	8	10. Did any of the babies in pregnancy #1 weigh less than 5.5 pounds at the time of birth?
123	p1f3q10_2	Num	8	10. Did any of the babies in pregnancy #2 weigh less than 5.5 pounds at the time of birth?
124	p1f3q10_3	Num	8	10. Did any of the babies in pregnancy #3 weigh less than 5.5 pounds at the time of birth?
125	p1f3q10_4	Num	8	10. Did any of the babies in pregnancy #4 weigh less than 5.5 pounds at the time of birth?
126	p1f3q10_5	Num	8	10. Did any of the babies in pregnancy #5 weigh less than 5.5 pounds at the time of birth?
127	p1f3q10_6	Num	8	10. Did any of the babies in pregnancy #6 weigh less than 5.5 pounds at the time of birth?
128	p1f3q10_7	Num	8	10. Did any of the babies in pregnancy #7 weigh less than 5.5 pounds at the time of birth?
129	p1f3q10_8	Num	8	10. Did any of the babies in pregnancy #8 weigh less than 5.5 pounds at the time of birth?
130	p1f3q10_9	Num	8	10. Did any of the babies in pregnancy #9 weigh less than 5.5 pounds at the time of birth?
131	p1f3q10_10	Num	8	10. Did any of the babies in pregnancy #10 weigh less than 5.5 pounds at the time of birth?
132	p1f3q10_11	Num	8	10. Did any of the babies in pregnancy #11 weigh less than 5.5 pounds at the time of birth?
133	p1f3q11_1	Num	8	11. Did a doctor ever say a baby from pregnancy #1 had low birth weight, a birth defect, a genetic condition, or another serious medical problem related to birth?
134	p1f3q11_2	Num	8	11. Did a doctor ever say a baby from pregnancy #2 had low birth weight, a birth defect, a genetic condition, or another serious medical problem related to birth?
135	p1f3q11_3	Num	8	11. Did a doctor ever say a baby from pregnancy #3 had low birth weight, a birth defect, a genetic condition, or another serious medical problem related to birth?
136	p1f3q11_4	Num	8	11. Did a doctor ever say a baby from pregnancy #4 had low birth weight, a birth defect, a genetic condition, or another serious medical problem related to birth?

Num	Variable	Type	Len	Label
137	p1f3q11_5	Num	8	11. Did a doctor ever say a baby from pregnancy #5 had low birth weight, a birth defect, a genetic condition, or another serious medical problem related to birth?
138	p1f3q11_6	Num	8	11. Did a doctor ever say a baby from pregnancy #6 had low birth weight, a birth defect, a genetic condition, or another serious medical problem related to birth?
139	p1f3q11_7	Num	8	11. Did a doctor ever say a baby from pregnancy #7 had low birth weight, a birth defect, a genetic condition, or another serious medical problem related to birth?
140	p1f3q11_8	Num	8	11. Did a doctor ever say a baby from pregnancy #8 had low birth weight, a birth defect, a genetic condition, or another serious medical problem related to birth?
141	p1f3q11_9	Num	8	11. Did a doctor ever say a baby from pregnancy #9 had low birth weight, a birth defect, a genetic condition, or another serious medical problem related to birth?
142	p1f3q11_10	Num	8	11. Did a doctor ever say a baby from pregnancy #10 had low birth weight, a birth defect, a genetic condition, or another serious medical problem related to birth?
143	p1f3q11_11	Num	8	11. Did a doctor ever say a baby from pregnancy #11 had low birth weight, a birth defect, a genetic condition, or another serious medical problem related to birth?
144	p1f3q12_1__1	Num	8	12. Had any significant medical complications during pregnancy #1? No complications
145	p1f3q12_2__1	Num	8	12. Had any significant medical complications during pregnancy #2? No complications
146	p1f3q12_3__1	Num	8	12. Had any significant medical complications during pregnancy #3? No complications
147	p1f3q12_4__1	Num	8	12. Had any significant medical complications during pregnancy #4? No complications
148	p1f3q12_5__1	Num	8	12. Had any significant medical complications during pregnancy #5? No complications
149	p1f3q12_6__1	Num	8	12. Had any significant medical complications during pregnancy #6? No complications
150	p1f3q12_7__1	Num	8	12. Had any significant medical complications during pregnancy #7? No complications
151	p1f3q12_8__1	Num	8	12. Had any significant medical complications during pregnancy #8? No complications
152	p1f3q12_9__1	Num	8	12. Had any significant medical complications during pregnancy #9? No complications
153	p1f3q12_10__1	Num	8	12. Had any significant medical complications during pregnancy #10? No complications
154	p1f3q12_11__1	Num	8	12. Had any significant medical complications during pregnancy #11? No complications
155	p1f3q12_1__2	Num	8	12. Had any significant medical complications during pregnancy #1? Pain crisis
156	p1f3q12_2__2	Num	8	12. Had any significant medical complications during pregnancy #2? Pain crisis
157	p1f3q12_3__2	Num	8	12. Had any significant medical complications during pregnancy #3? Pain crisis
158	p1f3q12_4__2	Num	8	12. Had any significant medical complications during pregnancy #4? Pain crisis
159	p1f3q12_5__2	Num	8	12. Had any significant medical complications during pregnancy #5? Pain crisis
160	p1f3q12_6__2	Num	8	12. Had any significant medical complications during pregnancy #6? Pain crisis
161	p1f3q12_7__2	Num	8	12. Had any significant medical complications during pregnancy #7? Pain crisis
162	p1f3q12_8__2	Num	8	12. Had any significant medical complications during pregnancy #8? Pain crisis
163	p1f3q12_9__2	Num	8	12. Had any significant medical complications during pregnancy #9? Pain crisis
164	p1f3q12_10__2	Num	8	12. Had any significant medical complications during pregnancy #10? Pain crisis
165	p1f3q12_11__2	Num	8	12. Had any significant medical complications during pregnancy #11? Pain crisis
166	p1f3q12_1__3	Num	8	12. Had any significant medical complications during pregnancy #1? Acute chest syndrome
167	p1f3q12_2__3	Num	8	12. Had any significant medical complications during pregnancy #2? Acute chest syndrome
168	p1f3q12_3__3	Num	8	12. Had any significant medical complications during pregnancy #3? Acute chest syndrome
169	p1f3q12_4__3	Num	8	12. Had any significant medical complications during pregnancy #4? Acute chest syndrome
170	p1f3q12_5__3	Num	8	12. Had any significant medical complications during pregnancy #5? Acute chest syndrome

Num	Variable	Type	Len	Label
171	p1f3q12_6__3	Num	8	12. Had any significant medical complications during pregnancy #6? Acute chest syndrome
172	p1f3q12_7__3	Num	8	12. Had any significant medical complications during pregnancy #7? Acute chest syndrome
173	p1f3q12_8__3	Num	8	12. Had any significant medical complications during pregnancy #8? Acute chest syndrome
174	p1f3q12_9__3	Num	8	12. Had any significant medical complications during pregnancy #9? Acute chest syndrome
175	p1f3q12_10__3	Num	8	12. Had any significant medical complications during pregnancy #10? Acute chest syndrome
176	p1f3q12_11__3	Num	8	12. Had any significant medical complications during pregnancy #11? Acute chest syndrome
177	p1f3q12_1__4	Num	8	12. Had any significant medical complications during pregnancy #1? Preeclampsia
178	p1f3q12_2__4	Num	8	12. Had any significant medical complications during pregnancy #2? Preeclampsia
179	p1f3q12_3__4	Num	8	12. Had any significant medical complications during pregnancy #3? Preeclampsia
180	p1f3q12_4__4	Num	8	12. Had any significant medical complications during pregnancy #4? Preeclampsia
181	p1f3q12_5__4	Num	8	12. Had any significant medical complications during pregnancy #5? Preeclampsia
182	p1f3q12_6__4	Num	8	12. Had any significant medical complications during pregnancy #6? Preeclampsia
183	p1f3q12_7__4	Num	8	12. Had any significant medical complications during pregnancy #7? Preeclampsia
184	p1f3q12_8__4	Num	8	12. Had any significant medical complications during pregnancy #8? Preeclampsia
185	p1f3q12_9__4	Num	8	12. Had any significant medical complications during pregnancy #9? Preeclampsia
186	p1f3q12_10__4	Num	8	12. Had any significant medical complications during pregnancy #10? Preeclampsia
187	p1f3q12_11__4	Num	8	12. Had any significant medical complications during pregnancy #11? Preeclampsia
188	p1f3q12_1__5	Num	8	12. Had any significant medical complications during pregnancy #1? Maternal diabetes
189	p1f3q12_2__5	Num	8	12. Had any significant medical complications during pregnancy #2? Maternal diabetes
190	p1f3q12_3__5	Num	8	12. Had any significant medical complications during pregnancy #3? Maternal diabetes
191	p1f3q12_4__5	Num	8	12. Had any significant medical complications during pregnancy #4? Maternal diabetes
192	p1f3q12_5__5	Num	8	12. Had any significant medical complications during pregnancy #5? Maternal diabetes
193	p1f3q12_6__5	Num	8	12. Had any significant medical complications during pregnancy #6? Maternal diabetes
194	p1f3q12_7__5	Num	8	12. Had any significant medical complications during pregnancy #7? Maternal diabetes
195	p1f3q12_8__5	Num	8	12. Had any significant medical complications during pregnancy #8? Maternal diabetes
196	p1f3q12_9__5	Num	8	12. Had any significant medical complications during pregnancy #9? Maternal diabetes
197	p1f3q12_10__5	Num	8	12. Had any significant medical complications during pregnancy #10? Maternal diabetes
198	p1f3q12_11__5	Num	8	12. Had any significant medical complications during pregnancy #11? Maternal diabetes
199	p1f3q12_1__6	Num	8	12. Had any significant medical complications during pregnancy #1? Transfusion required
200	p1f3q12_2__6	Num	8	12. Had any significant medical complications during pregnancy #2? Transfusion required
201	p1f3q12_3__6	Num	8	12. Had any significant medical complications during pregnancy #3? Transfusion required
202	p1f3q12_4__6	Num	8	12. Had any significant medical complications during pregnancy #4? Transfusion required
203	p1f3q12_5__6	Num	8	12. Had any significant medical complications during pregnancy #5? Transfusion required
204	p1f3q12_6__6	Num	8	12. Had any significant medical complications during pregnancy #6? Transfusion required
205	p1f3q12_7__6	Num	8	12. Had any significant medical complications during pregnancy #7? Transfusion required
206	p1f3q12_8__6	Num	8	12. Had any significant medical complications during pregnancy #8? Transfusion required
207	p1f3q12_9__6	Num	8	12. Had any significant medical complications during pregnancy #9? Transfusion required
208	p1f3q12_10__6	Num	8	12. Had any significant medical complications during pregnancy #10? Transfusion required
209	p1f3q12_11__6	Num	8	12. Had any significant medical complications during pregnancy #11? Transfusion required

Num	Variable	Type	Len	Label
210	p1f3q12_1__7	Num	8	12. Had any significant medical complications during pregnancy #1? Blood clots
211	p1f3q12_2__7	Num	8	12. Had any significant medical complications during pregnancy #2? Blood clots
212	p1f3q12_3__7	Num	8	12. Had any significant medical complications during pregnancy #3? Blood clots
213	p1f3q12_4__7	Num	8	12. Had any significant medical complications during pregnancy #4? Blood clots
214	p1f3q12_5__7	Num	8	12. Had any significant medical complications during pregnancy #5? Blood clots
215	p1f3q12_6__7	Num	8	12. Had any significant medical complications during pregnancy #6? Blood clots
216	p1f3q12_7__7	Num	8	12. Had any significant medical complications during pregnancy #7? Blood clots
217	p1f3q12_8__7	Num	8	12. Had any significant medical complications during pregnancy #8? Blood clots
218	p1f3q12_9__7	Num	8	12. Had any significant medical complications during pregnancy #9? Blood clots
219	p1f3q12_10__7	Num	8	12. Had any significant medical complications during pregnancy #10? Blood clots
220	p1f3q12_11__7	Num	8	12. Had any significant medical complications during pregnancy #11? Blood clots
221	p1f3q12_1__8	Num	8	12. Had any significant medical complications during pregnancy #1? Other
222	p1f3q12_2__8	Num	8	12. Had any significant medical complications during pregnancy #2? Other
223	p1f3q12_3__8	Num	8	12. Had any significant medical complications during pregnancy #3? Other
224	p1f3q12_4__8	Num	8	12. Had any significant medical complications during pregnancy #4? Other
225	p1f3q12_5__8	Num	8	12. Had any significant medical complications during pregnancy #5? Other
226	p1f3q12_6__8	Num	8	12. Had any significant medical complications during pregnancy #6? Other
227	p1f3q12_7__8	Num	8	12. Had any significant medical complications during pregnancy #7? Other
228	p1f3q12_8__8	Num	8	12. Had any significant medical complications during pregnancy #8? Other
229	p1f3q12_9__8	Num	8	12. Had any significant medical complications during pregnancy #9? Other
230	p1f3q12_10__8	Num	8	12. Had any significant medical complications during pregnancy #10? Other
231	p1f3q12_11__8	Num	8	12. Had any significant medical complications during pregnancy #11? Other
232	p1f3q12_1__9	Num	8	12. Had any significant medical complications during pregnancy #1? Pneumonia
233	p1f3q12_2__9	Num	8	12. Had any significant medical complications during pregnancy #2? Pneumonia
234	p1f3q12_3__9	Num	8	12. Had any significant medical complications during pregnancy #3? Pneumonia
235	p1f3q12_4__9	Num	8	12. Had any significant medical complications during pregnancy #4? Pneumonia
236	p1f3q12_5__9	Num	8	12. Had any significant medical complications during pregnancy #5? Pneumonia
237	p1f3q12_6__9	Num	8	12. Had any significant medical complications during pregnancy #6? Pneumonia
238	p1f3q12_7__9	Num	8	12. Had any significant medical complications during pregnancy #7? Pneumonia
239	p1f3q12_8__9	Num	8	12. Had any significant medical complications during pregnancy #8? Pneumonia
240	p1f3q12_9__9	Num	8	12. Had any significant medical complications during pregnancy #9? Pneumonia
241	p1f3q12_10__9	Num	8	12. Had any significant medical complications during pregnancy #10? Pneumonia
242	p1f3q12_11__9	Num	8	12. Had any significant medical complications during pregnancy #11? Pneumonia
243	p1f3q12_1__10	Num	8	12. Had any significant medical complications during pregnancy #1? Gall bladder issues
244	p1f3q12_2__10	Num	8	12. Had any significant medical complications during pregnancy #2? Gall bladder issues
245	p1f3q12_3__10	Num	8	12. Had any significant medical complications during pregnancy #3? Gall bladder issues
246	p1f3q12_4__10	Num	8	12. Had any significant medical complications during pregnancy #4? Gall bladder issues
247	p1f3q12_5__10	Num	8	12. Had any significant medical complications during pregnancy #5? Gall bladder issues
248	p1f3q12_6__10	Num	8	12. Had any significant medical complications during pregnancy #6? Gall bladder issues

Num	Variable	Type	Len	Label
249	p1f3q12_7__10	Num	8	12. Had any significant medical complications during pregnancy #7? Gall bladder issues
250	p1f3q12_8__10	Num	8	12. Had any significant medical complications during pregnancy #8? Gall bladder issues
251	p1f3q12_9__10	Num	8	12. Had any significant medical complications during pregnancy #9? Gall bladder issues
252	p1f3q12_10__10	Num	8	12. Had any significant medical complications during pregnancy #10? Gall bladder issues
253	p1f3q12_11__10	Num	8	12. Had any significant medical complications during pregnancy #11? Gall bladder issues
254	p1f3q12_1__11	Num	8	12. Had any significant medical complications during pregnancy #1? Liver issues
255	p1f3q12_2__11	Num	8	12. Had any significant medical complications during pregnancy #2? Liver issues
256	p1f3q12_3__11	Num	8	12. Had any significant medical complications during pregnancy #3? Liver issues
257	p1f3q12_4__11	Num	8	12. Had any significant medical complications during pregnancy #4? Liver issues
258	p1f3q12_5__11	Num	8	12. Had any significant medical complications during pregnancy #5? Liver issues
259	p1f3q12_6__11	Num	8	12. Had any significant medical complications during pregnancy #6? Liver issues
260	p1f3q12_7__11	Num	8	12. Had any significant medical complications during pregnancy #7? Liver issues
261	p1f3q12_8__11	Num	8	12. Had any significant medical complications during pregnancy #8? Liver issues
262	p1f3q12_9__11	Num	8	12. Had any significant medical complications during pregnancy #9? Liver issues
263	p1f3q12_10__11	Num	8	12. Had any significant medical complications during pregnancy #10? Liver issues
264	p1f3q12_11__11	Num	8	12. Had any significant medical complications during pregnancy #11? Liver issues
265	p1f3q12_1__12	Num	8	12. Had any significant medical complications during pregnancy #1? C-section
266	p1f3q12_2__12	Num	8	12. Had any significant medical complications during pregnancy #2? C-section
267	p1f3q12_3__12	Num	8	12. Had any significant medical complications during pregnancy #3? C-section
268	p1f3q12_4__12	Num	8	12. Had any significant medical complications during pregnancy #4? C-section
269	p1f3q12_5__12	Num	8	12. Had any significant medical complications during pregnancy #5? C-section
270	p1f3q12_6__12	Num	8	12. Had any significant medical complications during pregnancy #6? C-section
271	p1f3q12_7__12	Num	8	12. Had any significant medical complications during pregnancy #7? C-section
272	p1f3q12_8__12	Num	8	12. Had any significant medical complications during pregnancy #8? C-section
273	p1f3q12_9__12	Num	8	12. Had any significant medical complications during pregnancy #9? C-section
274	p1f3q12_10__12	Num	8	12. Had any significant medical complications during pregnancy #10? C-section
275	p1f3q12_11__12	Num	8	12. Had any significant medical complications during pregnancy #11? C-section
276	p1f3q12_1__13	Num	8	12. Had any significant medical complications during pregnancy #1? Respiratory issues
277	p1f3q12_2__13	Num	8	12. Had any significant medical complications during pregnancy #2? Respiratory issues
278	p1f3q12_3__13	Num	8	12. Had any significant medical complications during pregnancy #3? Respiratory issues
279	p1f3q12_4__13	Num	8	12. Had any significant medical complications during pregnancy #4? Respiratory issues
280	p1f3q12_5__13	Num	8	12. Had any significant medical complications during pregnancy #5? Respiratory issues
281	p1f3q12_6__13	Num	8	12. Had any significant medical complications during pregnancy #6? Respiratory issues
282	p1f3q12_7__13	Num	8	12. Had any significant medical complications during pregnancy #7? Respiratory issues
283	p1f3q12_8__13	Num	8	12. Had any significant medical complications during pregnancy #8? Respiratory issues
284	p1f3q12_9__13	Num	8	12. Had any significant medical complications during pregnancy #9? Respiratory issues
285	p1f3q12_10__13	Num	8	12. Had any significant medical complications during pregnancy #10? Respiratory issues
286	p1f3q12_11__13	Num	8	12. Had any significant medical complications during pregnancy #11? Respiratory issues
287	p1f3q12_1__14	Num	8	12. Had any significant medical complications during pregnancy #1? Seizures

Num	Variable	Type	Len	Label
288	p1f3q12_2__14	Num	8	12. Had any significant medical complications during pregnancy #2? Seizures
289	p1f3q12_3__14	Num	8	12. Had any significant medical complications during pregnancy #3? Seizures
290	p1f3q12_4__14	Num	8	12. Had any significant medical complications during pregnancy #4? Seizures
291	p1f3q12_5__14	Num	8	12. Had any significant medical complications during pregnancy #5? Seizures
292	p1f3q12_6__14	Num	8	12. Had any significant medical complications during pregnancy #6? Seizures
293	p1f3q12_7__14	Num	8	12. Had any significant medical complications during pregnancy #7? Seizures
294	p1f3q12_8__14	Num	8	12. Had any significant medical complications during pregnancy #8? Seizures
295	p1f3q12_9__14	Num	8	12. Had any significant medical complications during pregnancy #9? Seizures
296	p1f3q12_10__14	Num	8	12. Had any significant medical complications during pregnancy #10? Seizures
297	p1f3q12_11__14	Num	8	12. Had any significant medical complications during pregnancy #11? Seizures
298	p1f3q12_1__15	Num	8	12. Had any significant medical complications during pregnancy #1? Stroke
299	p1f3q12_2__15	Num	8	12. Had any significant medical complications during pregnancy #2? Stroke
300	p1f3q12_3__15	Num	8	12. Had any significant medical complications during pregnancy #3? Stroke
301	p1f3q12_4__15	Num	8	12. Had any significant medical complications during pregnancy #4? Stroke
302	p1f3q12_5__15	Num	8	12. Had any significant medical complications during pregnancy #5? Stroke
303	p1f3q12_6__15	Num	8	12. Had any significant medical complications during pregnancy #6? Stroke
304	p1f3q12_7__15	Num	8	12. Had any significant medical complications during pregnancy #7? Stroke
305	p1f3q12_8__15	Num	8	12. Had any significant medical complications during pregnancy #8? Stroke
306	p1f3q12_9__15	Num	8	12. Had any significant medical complications during pregnancy #9? Stroke
307	p1f3q12_10__15	Num	8	12. Had any significant medical complications during pregnancy #10? Stroke
308	p1f3q12_11__15	Num	8	12. Had any significant medical complications during pregnancy #11? Stroke
309	p1f3q12_1__16	Num	8	12. Had any significant medical complications during pregnancy #1? Infection
310	p1f3q12_2__16	Num	8	12. Had any significant medical complications during pregnancy #2? Infection
311	p1f3q12_3__16	Num	8	12. Had any significant medical complications during pregnancy #3? Infection
312	p1f3q12_4__16	Num	8	12. Had any significant medical complications during pregnancy #4? Infection
313	p1f3q12_5__16	Num	8	12. Had any significant medical complications during pregnancy #5? Infection
314	p1f3q12_6__16	Num	8	12. Had any significant medical complications during pregnancy #6? Infection
315	p1f3q12_7__16	Num	8	12. Had any significant medical complications during pregnancy #7? Infection
316	p1f3q12_8__16	Num	8	12. Had any significant medical complications during pregnancy #8? Infection
317	p1f3q12_9__16	Num	8	12. Had any significant medical complications during pregnancy #9? Infection
318	p1f3q12_10__16	Num	8	12. Had any significant medical complications during pregnancy #10? Infection
319	p1f3q12_11__16	Num	8	12. Had any significant medical complications during pregnancy #11? Infection
320	p1f3q12_1__17	Num	8	12. Had any significant medical complications during pregnancy #1? Anemia
321	p1f3q12_2__17	Num	8	12. Had any significant medical complications during pregnancy #2? Anemia
322	p1f3q12_3__17	Num	8	12. Had any significant medical complications during pregnancy #3? Anemia
323	p1f3q12_4__17	Num	8	12. Had any significant medical complications during pregnancy #4? Anemia
324	p1f3q12_5__17	Num	8	12. Had any significant medical complications during pregnancy #5? Anemia
325	p1f3q12_6__17	Num	8	12. Had any significant medical complications during pregnancy #6? Anemia
326	p1f3q12_7__17	Num	8	12. Had any significant medical complications during pregnancy #7? Anemia

Num	Variable	Type	Len	Label
327	p1f3q12_8__17	Num	8	12. Had any significant medical complications during pregnancy #8? Anemia
328	p1f3q12_9__17	Num	8	12. Had any significant medical complications during pregnancy #9? Anemia
329	p1f3q12_10__17	Num	8	12. Had any significant medical complications during pregnancy #10? Anemia
330	p1f3q12_11__17	Num	8	12. Had any significant medical complications during pregnancy #11? Anemia
331	p1f3q12_1__18	Num	8	12. Had any significant medical complications during pregnancy #1? Hypersmesis
332	p1f3q12_2__18	Num	8	12. Had any significant medical complications during pregnancy #2? Hypersmesis
333	p1f3q12_3__18	Num	8	12. Had any significant medical complications during pregnancy #3? Hypersmesis
334	p1f3q12_4__18	Num	8	12. Had any significant medical complications during pregnancy #4? Hypersmesis
335	p1f3q12_5__18	Num	8	12. Had any significant medical complications during pregnancy #5? Hypersmesis
336	p1f3q12_6__18	Num	8	12. Had any significant medical complications during pregnancy #6? Hypersmesis
337	p1f3q12_7__18	Num	8	12. Had any significant medical complications during pregnancy #7? Hypersmesis
338	p1f3q12_8__18	Num	8	12. Had any significant medical complications during pregnancy #8? Hypersmesis
339	p1f3q12_9__18	Num	8	12. Had any significant medical complications during pregnancy #9? Hypersmesis
340	p1f3q12_10__18	Num	8	12. Had any significant medical complications during pregnancy #10? Hypersmesis
341	p1f3q12_11__18	Num	8	12. Had any significant medical complications during pregnancy #11? Hypersmesis
342	p1f3q12_1__19	Num	8	12. Had any significant medical complications during pregnancy #1? Lost baby
343	p1f3q12_2__19	Num	8	12. Had any significant medical complications during pregnancy #2? Lost baby
344	p1f3q12_3__19	Num	8	12. Had any significant medical complications during pregnancy #3? Lost baby
345	p1f3q12_4__19	Num	8	12. Had any significant medical complications during pregnancy #4? Lost baby
346	p1f3q12_5__19	Num	8	12. Had any significant medical complications during pregnancy #5? Lost baby
347	p1f3q12_6__19	Num	8	12. Had any significant medical complications during pregnancy #6? Lost baby
348	p1f3q12_7__19	Num	8	12. Had any significant medical complications during pregnancy #7? Lost baby
349	p1f3q12_8__19	Num	8	12. Had any significant medical complications during pregnancy #8? Lost baby
350	p1f3q12_9__19	Num	8	12. Had any significant medical complications during pregnancy #9? Lost baby
351	p1f3q12_10__19	Num	8	12. Had any significant medical complications during pregnancy #10? Lost baby
352	p1f3q12_11__19	Num	8	12. Had any significant medical complications during pregnancy #11? Lost baby
353	p1f3q01	Num	8	1. had you ever been pregnant?
354	p1f3q02	Num	8	2. total number of pregnancies in your lifetime
355	p1f3q13	Num	8	13. Has there ever been a time in your life during which you didn't become pregnant despite 12 or more months of regular unprotected intercourse?
356	p1f3q14	Num	8	14. Did you ever go to a doctor or other medical care provider to talk about ways to help you had a baby?
357	p1f3q15__1	Num	8	15. Which of the services did you had to help you had a baby? Check all that apply. Advice
358	p1f3q15__2	Num	8	15. Which of the services did you had to help you had a baby? Check all that apply. Infertility testing
359	p1f3q15__3	Num	8	15. Which of the services did you had to help you had a baby? Check all that apply. Drugs to improve ovulation
360	p1f3q15__4	Num	8	15. Which of the services did you had to help you had a baby? Check all that apply. Surgery to correct blocked tubes
361	p1f3q15__5	Num	8	15. Which of the services did you had to help you had a baby? Check all that apply. Artificial insemination

Num	Variable	Type	Len	Label
362	p1f3q15__6	Num	8	15. Which of the services did you had to help you had a baby? Check all that apply. Other types of medical help
363	p1f3q16	Num	8	16. Has a doctor or other medical care provider ever told you that you had fibroid tumors or myomas in your uterus?
364	p1f3q17	Num	8	17. Has a doctor or other medical care provider ever told you that you had endometriosis?
365	newid	Char	8	Random ID
366	p1f3q03_1	Num	8	3. In what month and year did pregnancy #1 end (enter due date if currently pregnant)?
367	p1f3q03_2	Num	8	3. In what month and year did pregnancy #2 end (enter due date if currently pregnant)?
368	p1f3q03_3	Num	8	3. In what month and year did pregnancy #3 end (enter due date if currently pregnant)?
369	p1f3q03_4	Num	8	3. In what month and year did pregnancy #4 end (enter due date if currently pregnant)?
370	p1f3q03_5	Num	8	3. In what month and year did pregnancy #5 end (enter due date if currently pregnant)?
371	p1f3q03_6	Num	8	3. In what month and year did pregnancy #6 end (enter due date if currently pregnant)?
372	p1f3q03_7	Num	8	3. In what month and year did pregnancy #7 end (enter due date if currently pregnant)?
373	p1f3q03_8	Num	8	3. In what month and year did pregnancy #8 end (enter due date if currently pregnant)?
374	p1f3q03_9	Num	8	3. In what month and year did pregnancy #9 end (enter due date if currently pregnant)?
375	p1f3q03_10	Num	8	3. In what month and year did pregnancy #10 end (enter due date9 if currently pregnant)?
376	p1f3q03_11	Num	8	3. In what month and year did pregnancy #11 end (enter due date if currently pregnant)?

Data Set Name: *scdicregistry_malepreg.sas7bdat*

Num	Variable	Type	Len	Label
1	p1f4q01	Num	8	1. Have you ever fathered a baby?
2	p1f4q02	Num	8	total number of pregnancies where you have been the father
3	p1f4q03_1	Num	8	3.Pregnancy #1: In what month and year did this pregnancy end (or due date if currently pregnancy)?
4	p1f4q04_1	Num	8	4.Pregnancy #1: What was the outcome of this pregnancy?
5	p1f4q05_1	Num	8	5.Pregnancy #1: Were you taking hydroxyurea at the time of conception (when the pregnancy started) or within the month before conception?
6	p1f4q06_1	Num	8	6.Pregnancy #1: How many babies were born with this pregnancy?
7	p1f4q07_1	Num	8	7.Pregnancy #1: Was the baby (or babies) born prematurely?
8	p1f4q07a_1r	Num	8	Pregnancy #1: if born prematurely, how many weeks of gestation
9	p1f4q08_1	Num	8	8.Pregnancy #1: Did any of the babies in this pregnancy weigh less than 5. 5 pounds at the time of birth?
10	p1f4q09_1	Num	8	9.Pregnancy #1: Did a doctor ever say a baby from this pregnancy had low birth weight, a birth defect, a genetic condition, or another serious medical problem related to birth?
11	p1f4q03_2	Num	8	3.Pregnancy #2: In what month and year did this pregnancy end (or due date if currently pregnancy)?
12	p1f4q04_2	Num	8	4.Pregnancy #2: What was the outcome of this pregnancy?
13	p1f4q05_2	Num	8	5.Pregnancy #2: Were you taking hydroxyurea at the time of conception (when the pregnancy started) or within the month before conception?
14	p1f4q06_2	Num	8	6.Pregnancy #2: How many babies were born with this pregnancy?
15	p1f4q07_2	Num	8	7.Pregnancy #2: Was the baby (or babies) born prematurely?
16	p1f4q07a_2r	Num	8	Pregnancy #2: if born prematurely, how many weeks of gestation
17	p1f4q08_2	Num	8	8.Pregnancy #2: Did any of the babies in this pregnancy weigh less than 5. 5 pounds at the time of birth?
18	p1f4q09_2	Num	8	9.Pregnancy #2: Did a doctor ever say a baby from this pregnancy had low birth weight, a birth defect, a genetic condition, or another serious medical problem related to birth?
19	p1f4q03_3	Num	8	3.Pregnancy #3: In what month and year did this pregnancy end (or due date if currently pregnancy)?
20	p1f4q04_3	Num	8	4.Pregnancy #3: What was the outcome of this pregnancy?
21	p1f4q05_3	Num	8	5.Pregnancy #3: Were you taking hydroxyurea at the time of conception (when the pregnancy started) or within the month before conception?
22	p1f4q06_3	Num	8	6.Pregnancy #3: How many babies were born with this pregnancy?
23	p1f4q07_3	Num	8	7.Pregnancy #3: Was the baby (or babies) born prematurely?
24	p1f4q07a_3r	Num	8	Pregnancy #3: if born prematurely, how many weeks of gestation
25	p1f4q08_3	Num	8	8.Pregnancy #3: Did any of the babies in this pregnancy weigh less than 5. 5 pounds at the time of birth?
26	p1f4q09_3	Num	8	9.Pregnancy #3: Did a doctor ever say a baby from this pregnancy had low birth weight, a birth defect, a genetic condition, or another serious medical problem related to birth?
27	p1f4q03_4	Num	8	3.Pregnancy #4: In what month and year did this pregnancy end (or due date if currently pregnancy)?
28	p1f4q04_4	Num	8	4.Pregnancy #4: What was the outcome of this pregnancy?
29	p1f4q05_4	Num	8	5.Pregnancy #4: Were you taking hydroxyurea at the time of conception (when the pregnancy started) or within the month before conception?
30	p1f4q06_4	Num	8	6.Pregnancy #4: How many babies were born with this pregnancy?
31	p1f4q07_4	Num	8	7.Pregnancy #4: Was the baby (or babies) born prematurely?
32	p1f4q07a_4r	Num	8	Pregnancy #4: if born prematurely, how many weeks of gestation

Num	Variable	Type	Len	Label
33	p1f4q08_4	Num	8	8.Pregnancy #4: Did any of the babies in this pregnancy weigh less than 5. 5 pounds at the time of birth?
34	p1f4q09_4	Num	8	9.Pregnancy #4: Did a doctor ever say a baby from this pregnancy had low birth weight, a birth defect, a genetic condition, or another serious medical problem related to birth?
35	p1f4q03_5	Num	8	3.Pregnancy #5: In what month and year did this pregnancy end (or due date if currently pregnancy)?
36	p1f4q04_5	Num	8	4.Pregnancy #5: What was the outcome of this pregnancy?
37	p1f4q05_5	Num	8	5.Pregnancy #5: Were you taking hydroxyurea at the time of conception (when the pregnancy started) or within the month before conception?
38	p1f4q06_5	Num	8	6.Pregnancy #5: How many babies were born with this pregnancy?
39	p1f4q07_5	Num	8	7.Pregnancy #5: Was the baby (or babies) born prematurely?
40	p1f4q07a_5r	Num	8	Pregnancy #5: if born prematurely, how many weeks of gestation
41	p1f4q08_5	Num	8	8.Pregnancy #5: Did any of the babies in this pregnancy weigh less than 5. 5 pounds at the time of birth?
42	p1f4q09_5	Num	8	9.Pregnancy #5: Did a doctor ever say a baby from this pregnancy had low birth weight, a birth defect, a genetic condition, or another serious medical problem related to birth?
43	p1f4q03_6	Num	8	3.Pregnancy #6: In what month and year did this pregnancy end (or due date if currently pregnancy)?
44	p1f4q04_6	Num	8	4.Pregnancy #6: What was the outcome of this pregnancy?
45	p1f4q05_6	Num	8	5.Pregnancy #6: Were you taking hydroxyurea at the time of conception (when the pregnancy started) or within the month before conception?
46	p1f4q06_6	Num	8	6.Pregnancy #6: How many babies were born with this pregnancy?
47	p1f4q07_6	Num	8	7.Pregnancy #6: Was the baby (or babies) born prematurely?
48	p1f4q07a_6r	Num	8	Pregnancy #6: if born prematurely, how many weeks of gestation
49	p1f4q08_6	Num	8	8.Pregnancy #6: Did any of the babies in this pregnancy weigh less than 5. 5 pounds at the time of birth?
50	p1f4q09_6	Num	8	9.Pregnancy #6: Did a doctor ever say a baby from this pregnancy had low birth weight, a birth defect, a genetic condition, or another serious medical problem related to birth?
51	p1f4q03_7	Num	8	3.Pregnancy #7: In what month and year did this pregnancy end (or due date if currently pregnancy)?
52	p1f4q04_7	Num	8	4.Pregnancy #7: What was the outcome of this pregnancy?
53	p1f4q05_7	Num	8	5.Pregnancy #7: Were you taking hydroxyurea at the time of conception (when the pregnancy started) or within the month before conception?
54	p1f4q06_7	Num	8	6.Pregnancy #7: How many babies were born with this pregnancy?
55	p1f4q07_7	Num	8	7.Pregnancy #7: Was the baby (or babies) born prematurely?
56	p1f4q07a_7r	Num	8	Pregnancy #7: if born prematurely, how many weeks of gestation
57	p1f4q08_7	Num	8	8.Pregnancy #7: Did any of the babies in this pregnancy weigh less than 5. 5 pounds at the time of birth?
58	p1f4q09_7	Num	8	9.Pregnancy #7: Did a doctor ever say a baby from this pregnancy had low birth weight, a birth defect, a genetic condition, or another serious medical problem related to birth?
59	p1f4q03_8	Num	8	3.Pregnancy #8: In what month and year did this pregnancy end (or due date if currently pregnancy)?
60	p1f4q04_8	Num	8	4.Pregnancy #8: What was the outcome of this pregnancy?
61	p1f4q05_8	Num	8	5.Pregnancy #8: Were you taking hydroxyurea at the time of conception (when the pregnancy started) or within the month before conception?
62	p1f4q06_8	Num	8	6.Pregnancy #8: How many babies were born with this pregnancy?
63	p1f4q07_8	Num	8	7.Pregnancy #8: Was the baby (or babies) born prematurely?
64	p1f4q07a_8r	Num	8	Pregnancy #8: if born prematurely, how many weeks of gestation
65	p1f4q08_8	Num	8	8.Pregnancy #8: Did any of the babies in this pregnancy weigh less than 5. 5 pounds at the time of birth?

Num	Variable	Type	Len	Label
66	p1f4q09_8	Num	8	9.Pregnancy #8: Did a doctor ever say a baby from this pregnancy had low birth weight, a birth defect, a genetic condition, or another serious medical problem related to birth?
67	p1f4q10	Num	8	10. Have you ever had a painful continuous erection, which is also called priapism?
68	p1f4q11	Num	8	11. Has there ever been a time in your life during which you weren't able to get your partner pregnant despite 12 or more months of regular unprotected intercourse?
69	p1f4q12	Num	8	12. Did you ever go to a doctor or other medical care provider to talk about ways to help you father a baby?
70	p1f4q13__1	Num	8	13. Which of the following services did you have to help you father a baby? choice=Advice
71	p1f4q13__2	Num	8	13. Which of the following services did you have to help you father a baby? choice=Infertility testing
72	p1f4q13__3	Num	8	13. Which of the following services did you have to help you father a baby? choice=Surgery to reverse a vasectomy
73	p1f4q13__4	Num	8	13. Which of the following services did you have to help you father a baby? choice=Treatment for varicocele
74	p1f4q13__5	Num	8	13. Which of the following services did you have to help you father a baby? choice=Other types of medical help
75	p1f4q14__1	Num	8	14. When you went for medical help to father a baby, were you ever told that you had any of the following male infertility problems? Sperm or semen problems
76	p1f4q14__2	Num	8	14. When you went for medical help to father a baby, were you ever told that you had any of the following male infertility problems? Varicocele
77	p1f4q14__3	Num	8	14. When you went for medical help to father a baby, were you ever told that you had any of the following male infertility problems? Other
78	p1f4q14__4	Num	8	14. When you went for medical help to father a baby, were you ever told that you had any of the following male infertility problems? None of the above
79	newid	Char	8	Random ID

Data Set Name: *scdregistry_demographics.sas7bdat*

Num	Variable	Type	Len	Label
1	p1f6q02__1	Num	8	Race (check all that apply) American Indian or Alaska Native
2	p1f6q02__2	Num	8	Race (check all that apply) Asian, Native Hawaiian or Pacific Islander
3	p1f6q02__3	Num	8	Race (check all that apply) Black or African American
4	p1f6q02__5	Num	8	Race (check all that apply) White
5	p1f6q03	Num	8	3. Ethnicity (check one)
6	p1f6q04	Num	8	4. Sex
7	newid	Char	8	Random ID
8	RUCA1	Num	8	Primary RUCA code
9	RUCA2	Char	5	Secondary RUCA code
10	p1f7q01	Num	8	Off-study event
11	p1f7q01_4b	Num	8	Date of loss to follow-up
12	p1f7q03	Num	8	3. Date last known alive
13	p1f7q04	Num	8	4. Date of death
14	age_enroll	Num	8	Age at Enrollment

Data Set Name: *scdregistry_fulptsurvey.sas7bdat*

Num	Variable	Type	Len	Label
1	p2fl_opt_out__1	Num	8	The patient has opted out of taking this survey
2	p2flq00	Num	8	What is today's date?
3	p2flq01	Num	8	1. Do you take pain medicine every day for your sickle cell disease?
4	p2flq02__1	Num	8	2. What pain medicines do you currently take for your sickle cell disease? Dont take pain medicines.
5	p2flq03	Num	8	3. In the past 12 months, how many sickle cell pain attacks (crises) did you have?
6	p2flq04	Num	8	4. When was your last pain attack (crisis)?
7	p2flq05	Num	8	5. 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.
8	p2flq06	Num	8	6. How much did your last pain attack (crisis) interfere with your life?
9	p2flq07	Num	8	7. About how long did your most recent pain attack (crisis) last?
10	p2flq08a	Num	8	8a. In the past 7 days, how often did you have very severe pain?
11	p2flq08b	Num	8	8b. In the past 7 days, how often did you have pain so bad that it was hard to finish what you were doing?
12	p2flq09a	Num	8	9a. In the past 6 months, how often did you have very severe pain?
13	p2flq09b	Num	8	9b. In the past 6 months, how often did you have pain so bad that it was hard to finish what you were doing?
14	p2flq10a	Num	8	10a. In the past 7 days, did your pain feel like pins and needles?
15	p2flq10b	Num	8	10b. In the past 7 days, did your pain feel sore?
16	p2flq11	Num	8	11. Would you say that your pain management plan is....
17	p2flq12	Num	8	12. Do you get regular blood transfusions for your sickle cell disease?
18	p2flq13	Num	8	13. In the past 12 months, how many units (pints) of blood have you received?
19	p2flq14	Num	8	14. Are you currently on iron chelation treatment (e.g., Desferal, Exjade, Jadenu, deferasirox, Ferriprox, deferiprone, phlebotomy?)
20	p2flq15	Num	8	15. In the past 12 months, has your spleen been removed?
21	p2flq16a	Num	8	16a. In the past 12 months, have you been newly diagnosed with lung problems such as pneumonia or acute chest syndrome
22	p2flq16b	Num	8	16b. In the past 12 months, have you been newly diagnosed with kidney damage
23	p2flq16c	Num	8	16c. In the past 12 months, have you been newly diagnosed with eye damage called retinopathy
24	p2flq16d	Num	8	16d. In the past 12 months, have you been newly diagnosed with damage to your hip or shoulder due to sickle cell disease
25	p2flq16e	Num	8	16e. In the past 12 months, have you been newly diagnosed with high blood pressure in your lungs (also called pulmonary hypertension)
26	p2flq16f	Num	8	16f. In the past 12 months, have you been newly diagnosed with heart failure
27	p2flq16g	Num	8	16g. In the past 12 months, have you been newly diagnosed with blood clots in your legs or arms or that went to your lung
28	p2flq16h	Num	8	16h. In the past 12 months, have you been newly diagnosed with a stroke
29	p2flq16i	Num	8	16i. In the past 12 months, have you been newly diagnosed with asthma
30	p2flq16j	Num	8	16j. In the past 12 months, have you been newly diagnosed with diabetes
31	p2flq16k	Num	8	16k. In the past 12 months, have you been newly diagnosed with liver problems such as hepatitis, iron overload, or cirrhosis

Num	Variable	Type	Len	Label
32	p2flq16l	Num	8	16l. In the past 12 months, have you been newly diagnosed with skin ulcers
33	p2flq17	Num	8	19. In the past 12 months, have you taken hydroxyurea?
34	p2flq18	Num	8	20. Are you currently taking hydroxyurea?
35	p2flq19	Num	8	21. In the past 12 months, what is the reason you discontinued or stopped taking hydroxyurea?
36	p2flq20	Num	8	22. How many days did you take hydroxyurea in the PAST WEEK?
37	p2flq21__1	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Hair loss/thinning
38	p2flq21__2	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Nail blackening or discoloration
39	p2flq21__3	Num	8	23. 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)
40	p2flq21__4	Num	8	23. 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
41	p2flq21__5	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Nausea/vomiting
42	p2flq21__6	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Skin ulcers
43	p2flq21__7	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Weight gain
44	p2flq21__8	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Headaches or dizziness
45	p2flq21__9	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Fatigue/drowsiness
46	p2flq21__10	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea?No side effects
47	p2flq22__1	Num	8	24. 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
48	p2flq22__2	Num	8	24. 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
49	p2flq22__3	Num	8	24. 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
50	p2flq22__4	Num	8	24. 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
51	p2flq22__5	Num	8	24. 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
52	p2flq22__6	Num	8	24. 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
53	p2flq22__7	Num	8	24. 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
54	p2flq22__8	Num	8	24. 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
55	p2flq22__9	Num	8	24. 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
56	p2flq22__97	Num	8	24. 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

Num	Variable	Type	Len	Label
57	p2flq23	Num	8	25. In the past 12 months, have you taken the drug called Endari (l-glutamine)?
58	p2flq24	Num	8	26. Are you currently taking Endari?
59	p2flq25	Num	8	27. In the past 12 months, what is the reason you discontinued or stopped taking Endari? Please select one from the list below.
60	p2flq26	Num	8	28. How many days did you take Endari in the PAST WEEK?
61	p2flq27__1	Num	8	29. In the last 12 months, what side effects have you experienced while you were taking Endari? No side effects
62	p2flq27__2	Num	8	29. In the last 12 months, what side effects have you experienced while you were taking Endari? Nausea/vomiting
63	p2flq27__3	Num	8	29. In the last 12 months, what side effects have you experienced while you were taking Endari? Stomach pain
64	p2flq27__4	Num	8	29. In the last 12 months, what side effects have you experienced while you were taking Endari? Cough
65	p2flq27__5	Num	8	29. In the last 12 months, what side effects have you experienced while you were taking Endari? Headaches or dizziness
66	p2flq27__6	Num	8	29. In the last 12 months, what side effects have you experienced while you were taking Endari? Other not listed above
67	p2flq29	Num	8	41. Are you taking any medications for high blood pressure (hypertension) or for your heart?
68	p2flq30	Num	8	42. Are you taking any other type of medication that we did not already ask about?
69	p2flq31	Num	8	43. Are you currently participating in a study where you are taking a medicine for sickle cell?
70	p2flq32a	Num	8	32a. Think about your sleep in the past 7 days, how often did you stay up most of the night because you could not fall asleep?
71	p2flq32b	Num	8	32b. Think about your sleep in the past 7 days, how often did you have a lot of trouble falling asleep?
72	p2flq33a_v3	Num	8	33av3. I have someone who will listen to me when I need to talk
73	p2flq33b_v3	Num	8	33bv3. I have someone to confide in or talk to about myself or my problems
74	p2flq33c_v3	Num	8	33cv3. I have someone who makes me feel appreciated
75	p2flq33d_v3	Num	8	33dv3. I have someone to talk with when I have a bad day
76	p2flq33a	Num	8	33a. Think about how you felt in the past 7 days: I felt worthless.
77	p2flq33b	Num	8	33b. Think about how you felt in the past 7 days: I felt helpless.
78	p2flq33c	Num	8	33c. Think about how you felt in the past 7 days: I felt depressed.
79	p2flq33d	Num	8	33d. Think about how you felt in the past 7 days: I felt hopeless.
80	p2flq33e	Num	8	33e. Think about how you felt in the past 7 days: How often did you feel completely hopeless because of your health?
81	p2flq33f	Num	8	33f. Think about how you felt in the past 7 days: How often were you very worried about needing to go to the hospital?
82	p2flq33g	Num	8	33g. Think about how you felt in the past 7 days: I felt tired.
83	p2flq35a_v3	Num	8	35av3. In the past 7 days, how often did the following happen? I felt fearful
84	p2flq35b_v3	Num	8	35bv3. In the past 7 days, how often did the following happen? I found it hard to focus on anything other than my anxiety
85	p2flq35c_v3	Num	8	35cv3. In the past 7 days, how often did the following happen? My worries overwhelmed me
86	p2flq35d_v3	Num	8	35dv3. In the past 7 days, how often did the following happen? I felt uneasy

Num	Variable	Type	Len	Label
87	p2flq34a	Num	8	34a. In the past 7 days, how often did the following happen? I had to read something several times to understand it.
88	p2flq34b	Num	8	34b. In the past 7 days, how often did the following happen? My thinking was slow.
89	p2flq34c	Num	8	34c. In the past 7 days, how often did the following happen? I had to work really hard to pay attention or I would make a mistake.
90	p2flq34d	Num	8	34d. In the past 7 days, how often did the following happen? I had trouble concentrating.
91	p2flq35a	Num	8	35a. How much difficulty do you currently have doing the following things? Reading and following complex instructions (e.g., directions for a new medication)?
92	p2flq35b	Num	8	35b. How much difficulty do you currently have doing the following things? Planning for and keeping appointments that are not part of your weekly routine (e.g., therapy or doctor appointment, social gathering with friends/family)?
93	p2flq35c	Num	8	35c. How much difficulty do you currently have doing the following things? Managing your time to do most of your daily activities?
94	p2flq35d	Num	8	35d. How much difficulty do you currently have doing the following things? Learning new tasks or instructions?
95	p2flq36a	Num	8	35a. How much did you rely on others to take care of you because of your health?
96	p2flq36b	Num	8	35b. How much did your health make it hard for you to do things with your friends?
97	p2flq39a_v3	Num	8	39av3. In the past month, please describe how often... I feel alone and apart from others
98	p2flq39b_v3	Num	8	39bv3. In the past month, please describe how often... I feel left out
99	p2flq39c_v3	Num	8	39cv3. In the past month, please describe how often... I feel that I am no longer close to anyone
100	p2flq39d_v3	Num	8	39dv3. In the past month, please describe how often... I feel alone
101	p2flq39e_v3	Num	8	39ev3. In the past month, please describe how often... I feel lonely
102	p2flq39f_v3	Num	8	39fv3. In the past month, please describe how often... I feel isolated from others
103	p2flq40a_v3	Num	8	40av3. I tend to bounce back quickly after hard times
104	p2flq40b_v3	Num	8	40bv3. I have a hard time making it through stressful events
105	p2flq40c_v3	Num	8	40cv3. It does not take me long to recover from a stressful event
106	p2flq40d_v3	Num	8	40dv3. It is hard for me to snap back when something bad happens
107	p2flq40e_v3	Num	8	40ev3. I usually come through difficult times with little trouble
108	p2flq40f_v3	Num	8	40fv3. I tend to take a long time to get over set-backs in my life
109	p2flq41_1a_v3	Num	8	41av3. I general, how would you rate your physical health?
110	p2flq41_2b_v3	Num	8	41bv3. To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?
111	p2flq37	Num	8	54. How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?
112	p2flq38a	Num	8	38a. I can follow directions when my doctor changes my medications.
113	p2flq38b	Num	8	38b. I can take my medication when there is a change in my usual day (unexpected things happen).
114	p2flq38c	Num	8	38c. I can manage my medication without help.
115	p2flq38d	Num	8	38d. I can list my medications, including the doses and schedule.
116	p2flq39	Num	8	56. 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?
117	p2flq40__1	Num	8	57. 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

Num	Variable	Type	Len	Label
118	p2flq40__2	Num	8	57. 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 wouldnt accept your health insurance
119	p2flq40__3	Num	8	57. 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 wouldnt pay for the treatment
120	p2flq40__4	Num	8	57. 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 couldnt get an appointment soon enough
121	p2flq40__5	Num	8	57. 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 couldnt get there when the doctors office or clinic was open
122	p2flq40__6	Num	8	57. 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 doctors office or clinic from your house or work
123	p2flq40__7	Num	8	57. 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 couldnt get through on the telephone
124	p2flq40__8	Num	8	57. 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
125	p2flq40__9	Num	8	57. 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 didnt think the problem was serious enough
126	p2flq40__10	Num	8	57. 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
127	p2flq40__11	Num	8	57. 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 doctors office or clinic dont speak the same language I do
128	p2flq40__12	Num	8	57. 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
129	p2flq40__97	Num	8	57. 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)
130	p2flq46_v3	Num	8	58. How hard is it for you to pay for the very basics like food, housing, medical care, and heating?
131	p2flq47_v3	Num	8	59. Did you lose your health insurance in the past year?
132	newid	Char	8	Random ID
133	painmedscount	Num	8	Number of pain medications currently taking (Q2)
134	othermedscount	Num	8	Number of other medications currently taking (Q28)

Data Set Name: *scdregistry_fu2labform.sas7bdat*

Num	Variable	Type	Len	Label
1	p3f2q0___1	Num	8	FORM COMPLETE, LABORATORY RECORDS NOT AVAILABLE (choice=)
2	p3f2q1___1	Num	8	1. Nucleated RBC (choice=NA)
3	p3f2q1_1	Num	8	1. Nucleated RBC Test results
4	p3f2q1_1b	Num	8	1. Nucleated RBC Unit
5	p3f2q1_2	Num	8	1. Nucleated RBC Date of Most Recent
6	p3f2q2___1	Num	8	2. White Blood Cells (choice=NA)
7	p3f2q2_1	Num	8	2. White Blood Cells Test results
8	p3f2q2_2	Num	8	2. White Blood Cells Date of Most Recent
9	p3f2q3___1	Num	8	3. RBC (choice=NA)
10	p3f2q3_1	Num	8	3. RBC Test results
11	p3f2q3_2	Num	8	3. RBC Date of Most Recent
12	p3f2q4___1	Num	8	4. Hemoglobin (choice=NA)
13	p3f2q4_1	Num	8	4. Hemoglobin Test results
14	p3f2q4_2	Num	8	4. Hemoglobin Date of Most Recent
15	p3f2q5___1	Num	8	5. Hematocrit (choice=NA)
16	p3f2q5_1	Num	8	5. Hematocrit Test results
17	p3f2q5_2	Num	8	5. Hematocrit Date of Most Recent
18	p3f2q6___1	Num	8	6. MCV (choice=NA)
19	p3f2q6_1	Num	8	6. MCV Test results
20	p3f2q6_2	Num	8	6. MCV Date of Most Recent
21	p3f2q7___1	Num	8	7. MCH (choice=NA)
22	p3f2q7_1	Num	8	7. MCH Test results
23	p3f2q7_2	Num	8	7. MCH Date of Most Recent
24	p3f2q8___1	Num	8	8. MCHC (choice=NA)
25	p3f2q8_1	Num	8	8. MCHC Test results
26	p3f2q8_2	Num	8	8. MCHC Date of Most Recent
27	p3f2q9___1	Num	8	9. Platelets (choice=NA)
28	p3f2q9_1	Num	8	9. Platelets Test results
29	p3f2q9_2	Num	8	9. Platelets Date of Most Recent
30	p3f2q10___1	Num	8	10. Neutrophils (segmented and band together) (choice=NA)
31	p3f2q10_1	Num	8	10. Neutrophils Test results
32	p3f2q10_2	Num	8	10. Neutrophils Date of Most Recent
33	p3f2q11___1	Num	8	11. Lymphocytes (choice=NA)
34	p3f2q11_1	Num	8	11. Lymphocytes Test results
35	p3f2q11_2	Num	8	11. Lymphocytes Date of Most Recent
36	p3f2q12___1	Num	8	12. Monocytes (choice=NA)
37	p3f2q12_1	Num	8	12. Monocytes Test results

Num	Variable	Type	Len	Label
38	p3f2q12_2	Num	8	12. Monocytes Date of Most Recent
39	p3f2q13__1	Num	8	13. Reticulocytes (choice=NA)
40	p3f2q13_1	Num	8	13. Reticulocytes Test results
41	p3f2q13_4	Num	8	13. Reticulocytes Test results
42	p3f2q13_3	Num	8	13. Reticulocytes Date of Most Recent
43	p3f2q14__1	Num	8	14. Serum BUN (choice=NA)
44	p3f2q14_1	Num	8	14. Serum BUN Test results
45	p3f2q14_2	Num	8	14. Serum BUN Date of Most Recent
46	p3f2q15__1	Num	8	15. Serum Creatinine (choice=NA)
47	p3f2q15_1	Num	8	15. Serum Creatinine 15. Serum Creatinine Test results
48	p3f2q15_2	Num	8	15. Serum Creatinine Date of Most Recent
49	p3f2q17__1	Num	8	17. Estimated creatinine clearance (choice=NA)
50	p3f2q17_1	Num	8	17. Estimated creatinine clearance Test results
51	p3f2q17_2	Num	8	17. Estimated creatinine clearance Date of Most Recent
52	p3f2q18__1	Num	8	18. Total Cholesterol (choice=NA)
53	p3f2q18_1	Num	8	18. Total Cholesterol Test results
54	p3f2q18_2	Num	8	18. Total Cholesterol Date of Most Recent
55	p3f2q19__1	Num	8	19. Non-Fasting HDL (choice=NA)
56	p3f2q19_1	Num	8	19. Non-Fasting HDL Test results
57	p3f2q19_2	Num	8	19. Non-Fasting HDL Date of Most Recent
58	p3f2q20__1	Num	8	20. Fasting HDL (choice=NA)
59	p3f2q20_1	Num	8	20. Fasting HDL Test results
60	p3f2q20_2	Num	8	20. Fasting HDL Date of Most Recent
61	p3f2q21__1	Num	8	21. Non-Fasting LDL (choice=NA)
62	p3f2q21_1	Num	8	21. Non-Fasting LDL Test results
63	p3f2q21_2	Num	8	21. Non-Fasting LDL Date of Most Recent
64	p3f2q22__1	Num	8	22. Fasting LDL (choice=NA)
65	p3f2q22_1	Num	8	22. Fasting LDL Test results
66	p3f2q22_2	Num	8	22. Fasting LDL Date of Most Recent
67	p3f2q23__1	Num	8	23. Triglyceride (choice=NA)
68	p3f2q23_1	Num	8	23. Triglyceride Test results
69	p3f2q23_2	Num	8	23. Triglyceride Date of Most Recent
70	p3f2q24__1	Num	8	24. Non-Fasting Blood Glucose (choice=NA)
71	p3f2q24_1	Num	8	24. Non-Fasting Blood Glucose Test results
72	p3f2q24_2	Num	8	24. Non-Fasting Blood Glucose Date of Most Recent
73	p3f2q25__1	Num	8	25. Fasting Blood Glucose (choice=NA)
74	p3f2q25_1	Num	8	25. Fasting Blood Glucose Test results
75	p3f2q25_2	Num	8	25. Fasting Blood Glucose Date of Most Recent
76	p3f2q26__1	Num	8	26. CRP (choice=NA)

Num	Variable	Type	Len	Label
77	p3f2q26_1	Num	8	26. CRP Test results
78	p3f2q26_1a	Num	8	26. CRP Unit
79	p3f2q26_2	Num	8	26. CRP Date of Most Recent
80	p3f2q27__1	Num	8	27. Bilirubin serum, total (choice=NA)
81	p3f2q27_1	Num	8	27. Bilirubin serum, total Test results
82	p3f2q27_2	Num	8	27. Bilirubin serum, total Date of Most Recent
83	p3f2q28__1	Num	8	28. Bilirubin, serum, direct (choice=NA)
84	p3f2q28_1	Num	8	28. Bilirubin, serum, direct Test results
85	p3f2q28_2	Num	8	28. Bilirubin, serum, direct Date of Most Recent
86	p3f2q29__1	Num	8	29. AST (choice=NA)
87	p3f2q29_1	Num	8	29. AST Test results
88	p3f2q29_2	Num	8	29. AST Date of Most Recent
89	p3f2q30__1	Num	8	30. ALT (choice=NA)
90	p3f2q30_1	Num	8	30. ALT Test results
91	p3f2q30_2	Num	8	30. ALT Date of Most Recent
92	p3f2q31__1	Num	8	31. Alkaline Phosphatase (choice=NA)
93	p3f2q31_1	Num	8	31. Alkaline Phosphatase Test results
94	p3f2q31_2	Num	8	31. Alkaline Phosphatase Date of Most Recent
95	p3f2q32__1	Num	8	32. Total Protein (plasma) (choice=NA)
96	p3f2q32_1	Num	8	32. Total Protein (plasma) Test results
97	p3f2q32_2	Num	8	32. Total Protein (plasma) Date of Most Recent
98	p3f2q33__1	Num	8	33. Albumin (choice=NA)
99	p3f2q33_1	Num	8	33. Albumin Test results
100	p3f2q33_2	Num	8	33. Albumin Date of Most Recent
101	p3f2q34__1	Num	8	34. LDH (serum) (choice=NA)
102	p3f2q34_1	Num	8	34. LDH (serum) Test results
103	p3f2q34_2	Num	8	34. LDH (serum) Date of Most Recent
104	p3f2q35__1	Num	8	35. NT-pro-BNP (choice=NA)
105	p3f2q35_1	Num	8	35. NT-pro-BNP Test results
106	p3f2q35_2	Num	8	35. NT-pro-BNP Date of Most Recent
107	p3f2q36__1	Num	8	36. BNP (choice=NA)
108	p3f2q36_1	Num	8	36. BNP Test results
109	p3f2q36_2	Num	8	36. BNP Date of Most Recent
110	p3f2q37__1	Num	8	37. Serum iron (choice=NA)
111	p3f2q37_1	Num	8	37. Serum iron Test results
112	p3f2q37_2	Num	8	37. Serum iron Date of Most Recent
113	p3f2q38__1	Num	8	38. Total iron binding capacity (TIBC) (choice=NA)
114	p3f2q38_1	Num	8	38. Total iron binding capacity (TIBC) Test results
115	p3f2q38_2	Num	8	38. Total iron binding capacity (TIBC) Date of Most Recent

Num	Variable	Type	Len	Label
116	p3f2q39__1	Num	8	39. Serum transferrin (choice=NA)
117	p3f2q39_1	Num	8	39. Serum transferrin Test results
118	p3f2q39_1a	Num	8	39. Serum transferrin Unit
119	p3f2q39_2	Num	8	39. Serum transferrin Date of Most Recent
120	p3f2q40__1	Num	8	40. Ferritin (choice=NA)
121	p3f2q40_1	Num	8	40. Ferritin Test results
122	p3f2q40_2	Num	8	40. Ferritin Date of Most Recent
123	p3f2q41__1	Num	8	41. 25-Hydroxy Vitamin D (choice=NA)
124	p3f2q41_1	Num	8	41. 25-Hydroxy Vitamin D Test results
125	p3f2q41_2	Num	8	41. 25-Hydroxy Vitamin D Date of Most Recent
126	p3f2q42__1	Num	8	42. Erythropoietin (EPO) (choice=NA)
127	p3f2q42_1	Num	8	42. Erythropoietin (EPO) Test results
128	p3f2q42_2	Num	8	42. Erythropoietin (EPO) Date of Most Recent
129	p3f2q43__1	Num	8	43. Urine albumin (choice=NA)
130	p3f2q43_1	Num	8	43. Urine albumin Test results
131	p3f2q43_1a	Num	8	43. Urine albumin Unit
132	p3f2q43_2	Num	8	43. Urine albumin Date of Most Recent
133	p3f2q44__1	Num	8	44. Urine albumin / creatinine (choice=NA)
134	p3f2q44_1	Num	8	44. Urine albumin / creatinine Test results
135	p3f2q44_2	Num	8	44. Urine albumin / creatinine Date of Most Recent
136	p3f2q45__1	Num	8	45. Urine protein (dipstick) (choice=NA)
137	p3f2q45_1	Num	8	45. Urine protein (dipstick) Test results
138	p3f2q45_2	Num	8	45. Urine protein (dipstick) Date of Most Recent
139	p3f2q46__1	Num	8	46. Urine protein/creatinine (choice=NA)
140	p3f2q46_1	Num	8	46. Urine protein/creatinine (Test results
141	p3f2q46_2	Num	8	46. Urine protein/creatinine (Date of Most Recent
142	p3f2q47__1	Num	8	47. Urine dipstick heme (choice=NA)
143	p3f2q47_1	Num	8	47. Urine dipstick heme Test results
144	p3f2q47_2	Num	8	47. Urine dipstick heme Date of Most Recent
145	p3f2q48__1	Num	8	48. Urine microscopic RBCs (choice=NA)
146	p3f2q48_1r	Num	8	48. Urine microscopic RBCs Test results
147	p3f2q48_unit	Num	8	48. Urine microscopic RBCs Unit
148	p3f2q48_1r_2__1	Num	8	48. Urine microscopic RBCs (choice=>100 10^3/mm^3)
149	p3f2q48_2	Num	8	48. Urine microscopic RBCs Date of Most Recent
150	p3f2q49__1	Num	8	49. Urine microscopic WBCs (choice=NA)
151	p3f2q49_1r	Num	8	49. Urine microscopic WBCs Test results
152	p3f2q49_unit	Num	8	49. Urine microscopic WBCs Unit
153	p3f2q49_1r_2__1	Num	8	49. Urine microscopic WBCs (choice=>100 10^3/mm^3)
154	p3f2q49_2	Num	8	49. Urine microscopic WBCs Date of Most Recent

Num	Variable	Type	Len	Label
155	p3f2q50___1	Num	8	50. Hemoglobin fractionation, baseline(before HU use) (choice=NA)
156	p3f2q50_1	Num	8	50. Hemoglobin fractionation, baseline(before HU use) Hb A
157	p3f2q50_2	Num	8	50. Hemoglobin fractionation, baseline(before HU use) Hb A2
158	p3f2q50_3	Num	8	50. Hemoglobin fractionation, baseline(before HU use) Hb C
159	p3f2q50_4	Num	8	50. Hemoglobin fractionation, baseline(before HU use) Hb D
160	p3f2q50_5	Num	8	50. Hemoglobin fractionation, baseline(before HU use) Hb E
161	p3f2q50_6	Num	8	50. Hemoglobin fractionation, baseline(before HU use) Hb F
162	p3f2q50_7	Num	8	50. Hemoglobin fractionation, baseline(before HU use) Hb O
163	p3f2q50_8	Num	8	50. Hemoglobin fractionation, baseline(before HU use) Hb S
164	p3f2q50_10	Num	8	50. Hemoglobin fractionation, baseline(before HU use) other
165	p3f2q50_11	Num	8	50. Hemoglobin fractionation, baseline(before HU use) Date of Most Recent
166	p3f2q51___1	Num	8	51. Hemoglobin fractionation, most recent (choice=NA)
167	p3f2q51_1	Num	8	51. Hemoglobin fractionation, most recent Hb A
168	p3f2q51_2	Num	8	51. Hemoglobin fractionation, most recent Hb A2
169	p3f2q51_3	Num	8	51. Hemoglobin fractionation, most recent Hb C
170	p3f2q51_4	Num	8	51. Hemoglobin fractionation, most recent Hb D
171	p3f2q51_5	Num	8	51. Hemoglobin fractionation, most recent Hb E
172	p3f2q51_6	Num	8	51. Hemoglobin fractionation, most recent Hb F
173	p3f2q51_7	Num	8	51. Hemoglobin fractionation, most recent Hb O
174	p3f2q51_8	Num	8	51. Hemoglobin fractionation, most recent Hb S
175	p3f2q51_10	Num	8	51. Hemoglobin fractionation, most recent Other
176	p3f2q51_11	Num	8	51. Hemoglobin fractionation, most recent Date of Most Recent
177	p3f2q52___1	Num	8	52. Hemoglobin fractionation, maximum dose HU (choice=NA)
178	p3f2q52_1	Num	8	52. Hemoglobin fractionation, maximum dose HU Hb A
179	p3f2q52_2	Num	8	52. Hemoglobin fractionation, maximum dose HU Hb A2
180	p3f2q52_3	Num	8	52. Hemoglobin fractionation, maximum dose HU Hb C
181	p3f2q52_4	Num	8	52. Hemoglobin fractionation, maximum dose HU Hb D
182	p3f2q52_5	Num	8	52. Hemoglobin fractionation, maximum dose HU Hb E
183	p3f2q52_6	Num	8	52. Hemoglobin fractionation, maximum dose HU Hb F
184	p3f2q52_7	Num	8	52. Hemoglobin fractionation, maximum dose HU Hb O
185	p3f2q52_8	Num	8	52. Hemoglobin fractionation, maximum dose HU Hb S
186	p3f2q52_10	Num	8	52. Hemoglobin fractionation, maximum dose HU Other
187	p3f2q52_11	Num	8	52. Hemoglobin fractionation, maximum dose HU Date of Most Recent
188	newid	Char	8	Random ID

Data Set Name: *scdregistry_fu2mraform.sas7bdat*

Num	Variable	Type	Len	Label
1	p3f4q00a	Num	8	DATE FORM COMPLETED:
2	p3f4q04b__1	Num	8	MEDICAL RECORDS NOT AVAILABLE, FORM COMPLETE
3	p3f4q02a__1	Num	8	2a. Date of most recent visit to pediatric sickle cell provider. -DATE UNAVAILABLE
4	p3f4q02a_1	Num	8	2a. Date of most recent visit to pediatric sickle cell provider.
5	p3f4q02b__1	Num	8	2b. Date of first visit to adult sickle cell provider -has not seen adult provider
6	p3f4q02b__2	Num	8	2b. Date of first visit to adult sickle cell provider -date unavailable
7	p3f4q02b_1	Num	8	2b. Date of first visit to adult sickle cell provider.
8	p3f4q06__1	Num	8	4. Height -Not in record
9	p3f4q07__1	Num	8	5. Weight(KG) -Not in record
10	p3f4q08__1	Num	8	6. Temperature -Not in record
11	p3f4q08_1	Num	8	6. Temperature (Celsius)
12	p3f4q08_2	Num	8	6. Temperature -Date
13	p3f4q08_3	Num	8	6. Temperature -Steady state?
14	p3f4q09__1	Num	8	7. Heart Rate -Not in record
15	p3f4q09_1	Num	8	7. Heart Rate (Beats/Minute)-
16	p3f4q09_2	Num	8	7. Heart Rate -Date
17	p3f4q09_3	Num	8	7. Heart Rate -Steady state?
18	p3f4q10__1	Num	8	8. Respiration Rate - Not in record
19	p3f4q10_1	Num	8	8. Respiration Rate (Breaths/Minute)
20	p3f4q10_2	Num	8	8. Respiration Rate -Date
21	p3f4q10_3	Num	8	8. Respiration Rate -Steady state?
22	p3f4q11__1	Num	8	9. Oxygen Saturation Level-Not in record
23	p3f4q11_1	Num	8	9. Oxygen Saturation Level (SpO2)
24	p3f4q11_2	Num	8	9. Oxygen Saturation Level -Date
25	p3f4q11_3	Num	8	9. Oxygen Saturation Level -Steady state?
26	p3f4q12__1	Num	8	10. Blood Pressure (choice=Not in record)
27	p3f4q12_1	Num	8	10. Blood Pressure Systolic
28	p3f4q12_2	Num	8	10. Blood Pressure Diastolic
29	p3f4q12_3	Num	8	10. On anti-hypertensive meds?
30	p3f4q12_5	Num	8	10. Blood Pressure Date
31	p3f4q12_6	Num	8	10. Blood Pressure Steady state?
32	p3f4q13	Num	8	11. Has the subject started or stopped hydroxyurea since enrollment?
33	p3f4q13a	Num	8	11a. Hydroxyurea Start date
34	p3f4q13b_1__1	Num	8	11b. Hydroxyurea Stop/last date: Currently Using
35	p3f4q13b	Num	8	11b. Hydroxyurea Stop/last date
36	p3f4q12b	Num	8	12. Has the subject ever used Endari?
37	p3f4q12b_a	Num	8	12a. Endari Start date

Num	Variable	Type	Len	Label
38	p3f4q12b_b1__1	Num	8	12b.Endari Stop/last date:Currently Using
39	p3f4q12b_b	Num	8	12b. Endari Stop/last date
40	p3f4q13b2	Num	8	13. Has the subject ever used Crizanlizumab?
41	p3f4q13b2_a	Num	8	13a. Crizanlizumab Start date
42	p3f4q13b2_b1__1	Num	8	13b. Crizanlizumab Stop/last date: Currently Using
43	p3f4q13b2_b	Num	8	13b. Crizanlizumab Stop/last date
44	p3f4q14b	Num	8	14. Has the subject ever used Voxelator?
45	p3f4q14b_a	Num	8	14a. Voxelator Start date
46	p3f4q14b_b1__1	Num	8	14b. Voxelator Stop/last date: Currently Using
47	p3f4q14b_b	Num	8	14b. Voxelator Stop/last date
48	p3f4q15__1	Num	8	16. Acute Pain/Infusion Center (not admitted)=Not in record
49	p3f4q15_1	Num	8	16. Acute Pain/Infusion Center Visit/Admission Date
50	p3f4q15_2	Num	8	16. Acute Pain/Infusion Center Was visit for acute pain?
51	p3f4q16__1	Num	8	17. Emergency Department (not admitted) =Not in record
52	p3f4q16_1	Num	8	17. ED Visit/Admission Date
53	p3f4q16_2	Num	8	17. ED Was visit for acute pain?
54	p3f4q17__1	Num	8	18. Hospitalization =Not in record
55	p3f4q17_1	Num	8	18. Hospitalization Visit/Admission Date
56	p3f4q17_3	Num	8	18. Hospitalization Was visit for acute pain?
57	p3f4q18__1	Num	8	19. Primary care physician (i. e. family/internal medicine, pediatrician) Not in record
58	p3f4q18_1	Num	8	19. Primary care physician Visit Date
59	p3f4q19__1	Num	8	20. Behavioral medicine/psychiatrist =Not in record
60	p3f4q19_1	Num	8	20. ehavioral medicine/psychiatrist Visit Date
61	p3f4q20__1	Num	8	21. Hematologist =Not in record
62	p3f4q20_1	Num	8	21. Hematologist Visit Date
63	p3f4q21__1	Num	8	22. Orthopedic surgeon
64	p3f4q21_1	Num	8	22. Orthopedic surgeon Visit Date
65	p3f4q22__1	Num	8	23. Nephrologist =Not in record
66	p3f4q22_1	Num	8	23. Nephrologist Visit Date
67	p3f4q23__1	Num	8	24. Ophthalmologist =Not in record
68	p3f4q23_1	Num	8	24. Ophthalmologist Visit Date
69	p3f4q24__1	Num	8	25. Cardiologist =Not in record
70	p3f4q24_1	Num	8	25. Cardiologist Visit Date
71	p3f4q25__1	Num	8	26. Neurologist =Not in record
72	p3f4q25_1	Num	8	26. Neurologist Visit Date
73	p3f4q26__1	Num	8	27. Pulmonologist =Not in record
74	p3f4q26_1	Num	8	27. Pulmonologist Visit Date
75	p3f4q27__1	Num	8	28. OB/GYN =Not in record
76	p3f4q27_1	Num	8	28. OB/GYN Visit Date

Num	Variable	Type	Len	Label
77	p3f4q28__1	Num	8	29. Transfusion episodic, simple =None
78	p3f4q28_3	Num	8	29. Transfusion episodic, simple First time
79	p3f4q28_4	Num	8	29. Transfusion episodic, simple Last time
80	p3f4q28_5	Num	8	29. Transfusion episodic, simple Frequency
81	p3f4q29__1	Num	8	30. Transfusion chronic, simple =None
82	p3f4q29_3	Num	8	30. Transfusion chronic, simple First time
83	p3f4q29_4	Num	8	30. Transfusion chronic, simple Last time
84	p3f4q29_5	Num	8	30. Transfusion chronic, simple Reason stopped
85	p3f4q29_6	Num	8	30. Transfusion chronic, simple Frequency
86	p3f4q30__1	Num	8	31. Transfusion episodic, exchange =None
87	p3f4q30_2	Num	8	31. Transfusion episodic, exchange First time
88	p3f4q30_3	Num	8	31. Transfusion episodic, exchange Last time
89	p3f4q30_4	Num	8	31. Transfusion episodic, exchange Frequency
90	p3f4q30_5	Num	8	31. Transfusion episodic, exchange Type
91	p3f4q31__1	Num	8	32. Transfusion chronic, exchange =None
92	p3f4q31_2	Num	8	32. Transfusion chronic, exchange First time
93	p3f4q31_3	Num	8	32. Transfusion chronic, exchange Last time
94	p3f4q31_4	Num	8	32. Transfusion chronic, exchange Reason stopped
95	p3f4q31_5	Num	8	32. Transfusion chronic, exchange Frequency
96	p3f4q31_6	Num	8	32. Transfusion chronic, exchange Type
97	p3f4q33	Num	8	34. Dactylitis
98	p3f4q33_1	Num	8	34. Dactylitis Age most dx
99	p3f4q33_2	Num	8	34. Dactylitis date most recent dx
100	p3f4q34	Num	8	35. Osteomyelitis
101	p3f4q34_1	Num	8	35. Osteomyelitis Age most dx
102	p3f4q34_2	Num	8	35. Osteomyelitis date most recent dx
103	p3f4q35	Num	8	36. Chronic kidney disease
104	p3f4q35_1	Num	8	36. Chronic kidney disease Age most dx
105	p3f4q35_2	Num	8	36. Chronic kidney disease date most recent dx
106	p3f4q36	Num	8	37. End stage renal disease
107	p3f4q36_1	Num	8	37. End stage renal disease Age most dx
108	p3f4q36_2	Num	8	37. End stage renal disease date most recent dx
109	p3f4q37	Num	8	38. Priapism
110	p3f4q37_1	Num	8	38. Priapism Age most dx
111	p3f4q37_2	Num	8	38. Priapism date most recent dx
112	p3f4q41	Num	8	42. Left ventricular dysfunction
113	p3f4q41_1	Num	8	42. Left ventricular dysfunction Age most dx
114	p3f4q41_2	Num	8	42. Left ventricular dysfunction date most recent dx
115	p3f4q42	Num	8	43. Acute chest syndrome

Num	Variable	Type	Len	Label
116	p3f4q42_1	Num	8	43. Acute chest syndrome Age most dx
117	p3f4q42_2	Num	8	43. Acute chest syndrome date most recent dx
118	p3f4q43	Num	8	44. Asthma
119	p3f4q43_1	Num	8	44. Asthma Age most dx
120	p3f4q43_2	Num	8	44. Asthma date most recent dx
121	p3f4q44	Num	8	45. Gallstones/cholelithiasis, cholecystitis
122	p3f4q44_1	Num	8	45. Gallstones/cholelithiasis, cholecystitis Age most dx
123	p3f4q44_2	Num	8	45. Gallstones/cholelithiasis, cholecystitis date most recent dx
124	p3f4q54	Num	8	55. Skin ulcers (Integumentary)
125	p3f4q54_1	Num	8	55. Skin ulcers (Integumentary) Age most dx
126	p3f4q54_2	Num	8	55. Skin ulcers (Integumentary) date most recent dx
127	p3f4q55	Num	8	56. Retinopathy (Ocular)
128	p3f4q55_1	Num	8	56. Retinopathy (Ocular) Age most dx
129	p3f4q55_2	Num	8	56. Retinopathy (Ocular) date most recent dx
130	p3f4q56	Num	8	57. Diabetes mellitus (other systemic)
131	p3f4q56_1	Num	8	57. Diabetes mellitus (other systemic) Age most dx
132	p3f4q56_2	Num	8	57. Diabetes mellitus (other systemic) date most recent dx
133	p3f4q57	Num	8	58. Iron overload (Other)
134	p3f4q57_1	Num	8	58. Iron overload Age most dx
135	p3f4q57_2	Num	8	58. Iron overload date most recent dx
136	p3f4q58	Num	8	59. Chronic refractory pain (Other)
137	p3f4q58_1	Num	8	59. Chronic refractory pain Age most dx
138	p3f4q58_2	Num	8	59. Chronic refractory pain date most recent dx
139	p3f4q59	Num	8	60. Anxiety (Mental health)
140	p3f4q59_1	Num	8	60. Anxiety Age most dx
141	p3f4q59_2	Num	8	60. Anxiety date most recent dx
142	p3f4q60	Num	8	61. Depression (Mental health)
143	p3f4q60_1	Num	8	61. Depression Age most dx
144	p3f4q60_2	Num	8	61. Depression date most recent dx
145	p3f4q61	Num	8	62. Other psychiatric disorder (Mental health)
146	p3f4q61_2	Num	8	62. Other psychiatric disorder Age most dx
147	p3f4q61_3	Num	8	62. Other psychiatric disorder date most recent dx
148	p3f4q63b	Num	8	64. Has the subject ever had a Transcranial doppler test?
149	p3f4q63b_a	Num	8	64a. Transcranial doppler test Date of most recent
150	p3f4q63b_b	Num	8	64b. Transcranial doppler test Image available?
151	p3f4q63b_c	Num	8	64c. Transcranial doppler test Imaging report available?
152	p3f4q65	Num	8	65. Has the subject ever had a Brain MRI test?
153	p3f4q65a	Num	8	65a. Brain MRI test Date of most recent
154	p3f4q65b	Num	8	65b. Brain MRI test Image available?

Num	Variable	Type	Len	Label
155	p3f4q65c	Num	8	65c. Brain MRI test Imaging report available?
156	p3f4q66	Num	8	66. Has the subject ever had a Brain MRA test?
157	p3f4q66a	Num	8	66a. Brain MRA test Date of most recent
158	p3f4q66b	Num	8	66b. Brain MRA test Image available?
159	p3f4q66c	Num	8	66c. Brain MRA test Imaging report available?
160	p3f4q67	Num	8	67. Has the subject ever had an Outpatient cardiac ECHO test in last 3 years?
161	p3f4q67a	Num	8	67a. Outpatient cardiac ECHO test Date of most recent
162	p3f4q67b	Num	8	67b. Outpatient cardiac ECHO test Image available?
163	p3f4q67c	Num	8	67c. Outpatient cardiac ECHO test Imaging report available?
164	p3f4q68	Num	8	68. Has the subject ever had an Inpatient cardiac ECHO test in last 3 years?
165	p3f4q68a	Num	8	68a. Inpatient cardiac ECHO test Date of most recent
166	p3f4q68b	Num	8	68b. Inpatient cardiac ECHO test Image available?
167	p3f4q68c	Num	8	68c. Inpatient cardiac ECHO test Imaging report available?
168	p3f4q63__1	Num	8	69. What kind of health insurance or health care coverage does the subject currently have? Private health insurance
169	p3f4q63__2	Num	8	69. What kind of health insurance or health care coverage does the subject currently have? Medicare
170	p3f4q63__3	Num	8	69. 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.
171	p3f4q63__4	Num	8	69. What kind of health insurance or health care coverage does the subject currently have? TRICARE or other military health care, including VA health care
172	p3f4q63__5	Num	8	69. What kind of health insurance or health care coverage does the subject currently have? Other type of health insurance
173	newid	Char	8	Random ID
174	bmi	Num	8	BMI
175	bmi_dt	Num	8	BMI date
176	medscount	Num	8	Number of medications currently taking
177	p3f4q15_3R	Char	3	15. Acute Pain/Infusion Center- # of total visits in past year for acute pain/crisis (recoded)
178	p3f4q16_3R	Char	3	16. ED- # of total visits in past year for acute pain/crisis (recoded)
179	p3f4q17_2R	Char	3	17.Hospitalization-Length of stay (in days) (recoded)
180	p3f4q17_4R	Char	3	17.Hospitalization-# of total visits in past year for acute pain/crisis (recoded)
181	p3f4q05R	Num	8	3. Test results for alpha-thalassemia since enrollment? (recoded)
182	p3f4q28_1	Num	8	29. Transfusion episodic, simple # had
183	p3f4q28_2	Num	8	29. Transfusion episodic, simple # total units
184	p3f4q29_1	Num	8	30. Transfusion chronic, simple # had
185	p3f4q29_2	Num	8	30. Transfusion chronic, simple # total units
186	p3f4q30_1	Num	8	31. Transfusion episodic, exchange # had
187	p3f4q31_1	Num	8	32. Transfusion chronic, exchange # had
188	p3f4q32R	Num	8	33. Avascular necrosis (recoded)
189	p3f4q38R	Num	8	39. Stroke (recoded)

Num	Variable	Type	Len	Label
190	p3f4q40R	Num	8	41. Pulmonary arterial hypertension (recoded)
191	p3f4q45R	Num	8	46. Splenomegaly (recoded)
192	p3f4q52R	Num	8	53. Multi-organ failure (recoded)
193	p3f4q32R_age	Num	8	33. Avascular necrosis (recoded) most recent dx, age
194	p3f4q38R_age	Num	8	39. Stroke (recoded) most recent dx, age
195	p3f4q40R_age	Num	8	41. Pulmonary arterial hypertension (recoded) most recent dx,
196	p3f4q45R_age	Num	8	46. Splenomegaly (recoded) most recent dx, age
197	p3f4q52R_age	Num	8	53. Multi-organ failure (recoded) most recent dx, age
198	p3f4q32R_dt	Num	8	33. Avascular necrosis (recoded) most recent dx, date
199	p3f4q38R_dt	Num	8	39. Stroke (recoded) most recent dx, date
200	p3f4q40R_dt	Num	8	41. Pulmonary arterial hypertension (recoded) most recent dx, date
201	p3f4q45R_dt	Num	8	46. Splenomegaly (recoded) most recent dx, date
202	p3f4q52R_dt	Num	8	53. Multi-organ failure (recoded) most recent dx, date
203	AutoImm_Infany	Num	8	Any autoimmune/ inflammatory disease
204	AutoImm_Infany_age	Num	8	Any autoimmune/ inflammatory disease most recent dx, age
205	AutoImm_Infany_dt	Num	8	Any autoimmune/ inflammatory disease most recent dx, date

Data Set Name: *scdregistry_fu2ptsurvey.sas7bdat*

Num	Variable	Type	Len	Label
1	p3fl_opt_out__1	Num	8	The patient has opted out of taking this survey
2	p3flq00	Num	8	What is today's date?
3	p3flq01	Num	8	1. Do you take pain medicine every day for your sickle cell disease?
4	p3flq02__1	Num	8	2. What pain medicines do you currently take for your sickle cell disease? Dont take pain medicines.
5	p3flq03	Num	8	3. In the past 12 months, how many sickle cell pain attacks (crises) did you have?
6	p3flq04	Num	8	4. When was your last pain attack (crisis)?
7	p3flq05	Num	8	5. 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.
8	p3flq06	Num	8	6. How much did your last pain attack (crisis) interfere with your life?
9	p3flq07	Num	8	7. About how long did your most recent pain attack (crisis) last?
10	p3flq08a	Num	8	8a. How often did you have very severe pain?
11	p3flq08b	Num	8	8b. How often did you have pain so bad that it was hard to finish what you were doing?
12	p3flq09a	Num	8	9a. How often did you have very severe pain?
13	p3flq09b	Num	8	9b. How often did you have pain so bad that it was hard to finish what you were doing?
14	p3flq10a	Num	8	10a. Did your pain feel like pins and needles?
15	p3flq10b	Num	8	10b. Did your pain feel sore?
16	p3flq11	Num	8	11. Would you say that your pain management plan is....
17	p3flq12	Num	8	12. Do you get regular blood transfusions for your sickle cell disease?
18	p3flq13	Num	8	13. In the past 12 months, how many units (pints) of blood have you received?
19	p3flq14	Num	8	14. Are you currently on iron chelation treatment (e.g., Desferal, Exjade, Jadenu, deferasirox, Ferriprox, deferiprone, phlebotomy?)
20	p3flq15	Num	8	15. In the past 12 months, has your spleen been removed?
21	p3flq16a	Num	8	16a. In the past 12 months, have you been newly diagnosed with lung problems such as pneumonia or acute chest syndrome
22	p3flq16b	Num	8	16b. In the past 12 months, have you been newly diagnosed with kidney damage
23	p3flq16c	Num	8	16c. In the past 12 months, have you been newly diagnosed with eye damage called retinopathy
24	p3flq16d	Num	8	16d. In the past 12 months, have you been newly diagnosed with damage to your hip or shoulder due to sickle cell disease
25	p3flq16e	Num	8	16e. In the past 12 months, have you been newly diagnosed with high blood pressure in your lungs (also called pulmonary hypertension)
26	p3flq16f	Num	8	16f. In the past 12 months, have you been newly diagnosed with heart failure
27	p3flq16g	Num	8	16g. In the past 12 months, have you been newly diagnosed with blood clots in your legs or arms or that went to your lung
28	p3flq16h	Num	8	16h. In the past 12 months, have you been newly diagnosed with a stroke
29	p3flq16i	Num	8	16i. In the past 12 months, have you been newly diagnosed with asthma
30	p3flq16j	Num	8	16j. In the past 12 months, have you been newly diagnosed with diabetes
31	p3flq16k	Num	8	16k. In the past 12 months, have you been newly diagnosed with liver problems such as hepatitis, iron overload, or cirrhosis
32	p3flq16l	Num	8	16l. In the past 12 months, have you been newly diagnosed with skin ulcers

Num	Variable	Type	Len	Label
33	p3flq17	Num	8	19. In the past 12 months, have you taken hydroxyurea?
34	p3flq18	Num	8	20. Are you currently taking hydroxyurea?
35	p3flq19	Num	8	21. In the past 12 months, what is the reason you discontinued or stopped taking hydroxyurea?
36	p3flq20	Num	8	22. How many days did you take hydroxyurea in the PAST WEEK?
37	p3flq21__1	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Hair loss/thinning
38	p3flq21__2	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Nail blackening or discoloration
39	p3flq21__3	Num	8	23. 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)
40	p3flq21__4	Num	8	23. 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
41	p3flq21__5	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Nausea/vomiting
42	p3flq21__6	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Skin ulcers
43	p3flq21__7	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Weight gain
44	p3flq21__8	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Headaches or dizziness
45	p3flq21__9	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Fatigue/drowsiness
46	p3flq21__10	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? No side effects
47	p3flq22__1	Num	8	24. 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
48	p3flq22__2	Num	8	24. 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
49	p3flq22__3	Num	8	24. 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
50	p3flq22__4	Num	8	24. 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
51	p3flq22__5	Num	8	24. 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
52	p3flq22__6	Num	8	24. 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
53	p3flq22__7	Num	8	24. 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
54	p3flq22__8	Num	8	24. 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
55	p3flq22__9	Num	8	24. 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
56	p3flq22__97	Num	8	24. 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
57	p3flq23	Num	8	25. In the past 12 months, have you taken the drug called Endari (l-glutamine)?

Num	Variable	Type	Len	Label
58	p3flq24	Num	8	26. Are you currently taking Endari?
59	p3flq25	Num	8	27. In the past 12 months, what is the reason you discontinued or stopped taking Endari? Please select one from the list below.
60	p3flq26	Num	8	28. How many days did you take Endari in the PAST WEEK?
61	p3flq27__1	Num	8	29. In the last 12 months, what side effects have you experienced while you were taking Endari? No side effects
62	p3flq27__2	Num	8	29. In the last 12 months, what side effects have you experienced while you were taking Endari? Nausea/vomiting
63	p3flq27__3	Num	8	29. In the last 12 months, what side effects have you experienced while you were taking Endari? Stomach pain
64	p3flq27__4	Num	8	29. In the last 12 months, what side effects have you experienced while you were taking Endari? Cough
65	p3flq27__5	Num	8	29. In the last 12 months, what side effects have you experienced while you were taking Endari? Headaches or dizziness
66	p3flq27__6	Num	8	29. In the last 12 months, what side effects have you experienced while you were taking Endari? Other not listed above
67	p3flq30_v2f4	Num	8	30. In the past 12 months, have you taken the drug called Adakveo (crizanlizumab)?
68	p3flq31_v2f4	Num	8	31. Are you currently taking Adakveo?
69	p3flq32_v2f4	Num	8	32. In the past 12 months, what is the reason you discontinued or stopped taking Adakveo?
70	p3flq33_v2f4	Num	8	33. How many infusions of Adakveo have you missed or rescheduled in the PAST 6 MONTHS?
71	p3flq34_v2f4__1	Num	8	34. In the last 12 months, what side effects have you experienced while you were taking Adakveo? No side effects
72	p3flq34_v2f4__2	Num	8	34. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Fever
73	p3flq34_v2f4__3	Num	8	34. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Chills or shivering
74	p3flq34_v2f4__4	Num	8	34. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Nausea
75	p3flq34_v2f4__5	Num	8	34. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Vomiting
76	p3flq34_v2f4__6	Num	8	34. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Shortness of breath
77	p3flq34_v2f4__7	Num	8	34. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Muscle aches (myalias)
78	p3flq34_v2f4__8	Num	8	34. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Other not listed above
79	p3flq35_v2f4	Num	8	35. In the past 12 months, have you taken the drug called Oxbryta (voxelotor)?
80	p3flq36_v2f4	Num	8	36. Are you currently taking Oxbryta?
81	p3flq38_v2f4	Num	8	38. How many days did you take Oxbryta in the PAST WEEK?
82	p3flq39_v2f4__1	Num	8	39. In the last 12 months, what side effects have you experienced while you were taking Oxbryta? No side effects
83	p3flq39_v2f4__2	Num	8	39. In the last 12 months, what side effects have you experienced while you were taking Oxbryta? Rash or hives
84	p3flq39_v2f4__3	Num	8	39. In the last 12 months, what side effects have you experienced while you were taking Oxbryta? Headache

Num	Variable	Type	Len	Label
85	p3flq39_v2f4__4	Num	8	39. In the last 12 months, what side effects have you experienced while you were taking Oxbryta? Nausea
86	p3flq39_v2f4__5	Num	8	39. In the last 12 months, what side effects have you experienced while you were taking Oxbryta? Abdominal pain
87	p3flq39_v2f4__6	Num	8	39. In the last 12 months, what side effects have you experienced while you were taking Oxbryta? Loose stools
88	p3flq39_v2f4__7	Num	8	39. In the last 12 months, what side effects have you experienced while you were taking Oxbryta? Other not listed above
89	p3flq29	Num	8	41. Are you taking any medications for high blood pressure (hypertension) or for your heart?
90	p3flq30	Num	8	42. Are you taking any other type of medication that we did not already ask about?
91	p3flq31	Num	8	43. Are you currently participating in a study where you are taking a medicine for sickle cell?
92	p3flq32a	Num	8	32a. How often did you stay up most of the night because you could not fall asleep?
93	p3flq32b	Num	8	32b. How often did you have a lot of trouble falling asleep?
94	p3flq33a_v3_2	Num	8	33av3. I have someone who will listen to me when I need to talk
95	p3flq33b_v3_2	Num	8	33bv3. I have someone to confide in or talk to about myself or my problems
96	p3flq33c_v3_2	Num	8	33cv3. I have someone who makes me feel appreciated
97	p3flq33d_v3_2	Num	8	33dv3. I have someone to talk with when I have a bad day
98	p3flq33a	Num	8	33a. I felt worthless.
99	p3flq33b	Num	8	33b. I felt helpless.
100	p3flq33c	Num	8	33c. I felt depressed.
101	p3flq33d	Num	8	33d. I felt hopeless.
102	p3flq33e	Num	8	33e. How often did you feel completely hopeless because of your health?
103	p3flq33f	Num	8	33f. How often were you very worried about needing to go to the hospital?
104	p3flq33g	Num	8	33g. I felt tired.
105	p3flq35a_v3_2	Num	8	35av3. I felt fearful
106	p3flq35b_v3_2	Num	8	35bv3. I found it hard to focus on anything other than my anxiety
107	p3flq35c_v3_2	Num	8	35cv3. My worries overwhelmed me
108	p3flq35d_v3_2	Num	8	35dv3. I felt uneasy
109	p3flq34a	Num	8	34a. I had to read something several times to understand it.
110	p3flq34b	Num	8	34b. My thinking was slow.
111	p3flq34c	Num	8	34c. I had to work really hard to pay attention or I would make a mistake.
112	p3flq34d	Num	8	34d. I had trouble concentrating.
113	p3flq35a	Num	8	35a. Reading and following complex instructions (e.g., directions for a new medication)?
114	p3flq35b	Num	8	35b. Planning for and keeping appointments that are not part of your weekly routine (e.g., therapy or doctor appointment, social gathering with friends/family)?
115	p3flq35c	Num	8	35c. Managing your time to do most of your daily activities?
116	p3flq35d	Num	8	35d. Learning new tasks or instructions?
117	p3flq36a	Num	8	35a. How much did you rely on others to take care of you because of your health?
118	p3flq36b	Num	8	35b. How much did your health make it hard for you to do things with your friends?
119	p3flq39a_v3_2	Num	8	39av3. I feel alone and apart from others

Num	Variable	Type	Len	Label
120	p3flq39b_v3_2	Num	8	39bv3. I feel left out
121	p3flq39c_v3_2	Num	8	39cv3. I feel that I am no longer close to anyone
122	p3flq39d_v3_2	Num	8	39dv3. I feel alone
123	p3flq39e_v3_2	Num	8	39ev3. I feel lonely
124	p3flq39f_v3_2	Num	8	39fv3. I feel isolated from others
125	p3flq40a_v3_2	Num	8	40av3. I tend to bounce back quickly after hard times
126	p3flq40b_v3_2	Num	8	40bv3. I have a hard time making it through stressful events
127	p3flq40c_v3_2	Num	8	40cv3. It does not take me long to recover from a stressful event
128	p3flq40d_v3_2	Num	8	40dv3. It is hard for me to snap back when something bad happens
129	p3flq40e_v3_2	Num	8	40ev3. I usually come through difficult times with little trouble
130	p3flq40f_v3_2	Num	8	40fv3. I tend to take a long time to get over set-backs in my life
131	p3flq37_1a	Num	8	a. In general, how would you rate your physical health?
132	p3flq37_2b	Num	8	b. To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?
133	p3flq37	Num	8	54. 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	p3flq38a	Num	8	38a. I can follow directions when my doctor changes my medications.
135	p3flq38b	Num	8	38b. I can take my medication when there is a change in my usual day (unexpected things happen).
136	p3flq38c	Num	8	38c. I can manage my medication without help.
137	p3flq38d	Num	8	38d. I can list my medications, including the doses and schedule.
138	p3flq39	Num	8	56. 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?
139	p3flq40__1	Num	8	57. 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
140	p3flq40__2	Num	8	57. 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 wouldnt accept your health insurance
141	p3flq40__3	Num	8	57. 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 wouldnt pay for the treatment
142	p3flq40__4	Num	8	57. 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 couldnt get an appointment soon enough
143	p3flq40__5	Num	8	57. 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 couldnt get there when the doctors office or clinic was open
144	p3flq40__6	Num	8	57. 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 doctors office or clinic from your house or work
145	p3flq40__7	Num	8	57. 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 couldnt get through on the telephone

Num	Variable	Type	Len	Label
146	p3flq40__8	Num	8	57. 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
147	p3flq40__9	Num	8	57. 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 didnt think the problem was serious enough
148	p3flq40__10	Num	8	57. 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
149	p3flq40__11	Num	8	57. 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 doctors office or clinic dont speak the same language I do
150	p3flq40__12	Num	8	57. 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
151	p3flq40__97	Num	8	57. 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
152	p3flq46_v3_2	Num	8	58. How hard is it for you to pay for the very basics like food, housing, medical care, and heating?
153	p3flq47_v3_2	Num	8	59. Did you lose your health insurance in the past year?
154	p3flq48_a1_v3_2	Num	8	48av3_2. Experienced discrimination because of your race, ethnicity, or color in any of these situation: at school?
155	p3flq48_a2_v3_2	Num	8	48av3_2. How many times did this happen in the past 12 months?
156	p3flq48_b1_v3_2	Num	8	48bv3_2. Experienced discrimination because of your race, ethnicity, or color in any of these situation: getting hired or getting a job?
157	p3flq48_b2_v3_2	Num	8	48bv3_2. How many times did this happen in the past 12 months?
158	p3flq48_c1_v3_2	Num	8	48cv3_2. Experienced discrimination because of your race, ethnicity, or color in any of these situation: at work?
159	p3flq48_c2_v3_2	Num	8	48cv3_2. How many times did this happen in the past 12 months?
160	p3flq48_d1_v3_2	Num	8	48dv3_2. Experienced discrimination because of your race, ethnicity, or color in any of these situation: getting housing?
161	p3flq48_d2_v3_2	Num	8	48dv3_2. How many times did this happen in the past 12 months?
162	p3flq48_e1_v3_2	Num	8	48ev3_2. Experienced discrimination because of your race, ethnicity, or color in any of these situation: getting medical care?
163	p3flq48_e2_v3_2	Num	8	48ev3_2. How many times did this happen in the past 12 months?
164	p3flq48_f1_v3_2	Num	8	48fv3_2. Experienced discrimination because of your race, ethnicity, or color in any of these situation: getting service in a store or restaurant?
165	p3flq48_f2_v3_2	Num	8	48fv3_2. How many times did this happen in the past 12 months?
166	p3flq48_g1_v3_2	Num	8	48gv3_2. Experienced discrimination because of your race, ethnicity, or color in any of these situation: getting credit, bank loans, or a mortgage?
167	p3flq48_g2_v3_2	Num	8	48gv3_2. How many times did this happen in the past 12 months?
168	p3flq48_h1_v3_2	Num	8	48hv3_2. Experienced discrimination because of your race, ethnicity, or color in any of these situation: on the street or in a public setting?
169	p3flq48_h2_v3_2	Num	8	48hv3_2. How many times did this happen in the past 12 months?
170	p3flq48_i1_v3_2	Num	8	48iv3_2. Experienced discrimination because of your race, ethnicity, or color in any of these situation: from the police or in the courts?

Num	Variable	Type	Len	Label
171	p3flq48_i2_v3_2	Num	8	48iv3_2. How many times did this happen in the past 12 months?
172	newid	Char	8	Random ID
173	painmedscount	Num	8	Number of pain medications currently taking (Q2)
174	othermedscount	Num	8	Number of other medications currently taking (Q28)

Data Set Name: *scdregistry_fu2pulmonaryht.sas7bdat*

Num	Variable	Type	Len	Label
1	newid	Char	8	Random ID
2	p3f3q00	Num	8	Date Form Completed
3	p3f3q00_1	Char	7	Date of cardiac ECHO used to complete this form:
4	p3f3q00_2__1	Num	8	Type of cardiac ECHO used to complete this form: out-patient cardiac ECHO
5	p3f3q00_2__2	Num	8	Type of cardiac ECHO used to complete this form: in-patient cardiac ECHO
6	p3f3q01	Num	8	1. Mitral regurgitation: Qualitative data
7	p3f3q02	Num	8	2. Tricuspid regurgitation: Qualitative data
8	p3f3q03_a__1	Num	8	3. TR jet velocity: NA
9	p3f3q03	Num	8	3. TR jet velocity: Quantitative data
10	p3f3q03_b	Num	8	3. TR jet velocity: Unit
11	p3f3q04_a__1	Num	8	4. Tricuspid Annular Plane Systolic Excursion: NA
12	p3f3q04	Num	8	4. Tricuspid Annular Plane Systolic Excursion: Quantitative data
13	p3f3q05_a__1	Num	8	5. Ejection fraction, left ventricle: NA
14	p3f3q05	Num	8	5. Ejection fraction, left ventricle: Quantitative data
15	p3f3q06__1	Num	8	6. Left Atrial Volume: NA
16	p3f3q06_a_na__1	Num	8	6. Left Atrial Volume Qualitative data: NA
17	p3f3q06_a	Num	8	6. Left Atrial Volume Qualitative data
18	p3f3q06_b_na__1	Num	8	6. Left Atrial Volume Quantitative data: NA
19	p3f3q06_b	Num	8	6. Left Atrial Volume: LAESVI
20	p3f3q07__1	Num	8	7. Right Atrial Volume: NA
21	p3f3q07_a	Num	8	7. Right Atrial Volume Qualitative data
22	p3f3label3c__0	Num	8	7. Right Atrial Volume Quantitative data: NA
23	p3f3q07_b	Num	8	7. Right Atrial Volume: RAESVI
24	p3f3q08__1	Num	8	8. Left ventricular volume: NA
25	p3f3q08_a	Num	8	8. Left ventricular volume: Qualitative data
26	p3f3label8_2__0	Num	8	8. Left ventricular volumeQuantitative data: NA
27	p3f3q08_b1	Num	8	Left ventricular end systolic dimension: LVIDs
28	p3f3q08_b1b	Num	8	Left ventricular end systolic dimension: LVIDs Unit
29	p3f3q08_b2	Num	8	Left ventricular end systolic dimension: LVESVI
30	p3f3q08_b3	Num	8	Left ventricular end diastolic dimension: LVIDd
31	p3f3q08_b3b	Num	8	Left ventricular end diastolic dimension: LVIDd Unit
32	p3f3q08_b4	Num	8	Left ventricular end diastolic dimension: LVPwD
33	p3f3q08_b4b	Num	8	Left ventricular end diastolic dimension: LVPwD Unit
34	p3f3q09__1	Num	8	9. Right ventricular volume: NA
35	p3f3q09_a	Num	8	9. Right ventricular volume: Qualitative data
36	p3f3label9_2__0	Num	8	9. Right ventricular volume Quantitative data: NA
37	p3f3q09_b2	Num	8	9. Right ventricular volume: RVIDd

Num	Variable	Type	Len	Label
38	p3f3q09_b3	Num	8	9. Right ventricular volume:Mention of interventricular septal flattening
39	p3f3q10_a__1	Num	8	10. RV hypertrophy: NA
40	p3f3q10	Num	8	10. RV hypertrophy: Qualitative data
41	p3f3q11__1	Num	8	11. Most recent EKG: EKG not available
42	p3f3q11_2	Char	5	11. Date of Most recent EKG
43	p3f3q11_a	Num	8	11. Arrhythmia diagnosed?
44	p3f3q12_a__1	Num	8	12. Ventricular rate: NA
45	p3f3q12_b	Num	8	12. Ventricular rate
46	p3f3q13_a__1	Num	8	13. PR Interval: NA
47	p3f3q13_b	Num	8	13. PR Interval
48	p3f3q14_a__1	Num	8	14. QRS duration (choice=NA)
49	p3f3q14_b	Num	8	14. QRS duration
50	p3f3q15_a__1	Num	8	15. QT/QTc: NA
51	p3f3q15_b	Char	9	15. QT/QTc
52	p3f3q16_a__1	Num	8	16. P-R-T axes: NA
53	p3f3q16_b	Char	15	16. P-R-T axes
54	p3f3q17_1__1	Num	8	17. Most recent right heart catheterization: Report not available
55	p3f3q17_2	Char	5	17. Date of most recent right heart catheterization
56	p3f3q17_a__1	Num	8	17. RA pressure (mean): NA
57	p3f3q17_b	Num	8	17. RA pressure (mean)
58	p3f3q18_a__1	Num	8	18. RV pressure (mean): NA
59	p3f3q18_b	Num	8	18. RV pressure (mean)
60	p3f3q19_a__1	Num	8	19. PA pressure (mean): NA
61	p3f3q19_b	Num	8	19. PA pressure (mean)
62	p3f3q20_a__1	Num	8	20. Pulmonary artery saturation: NA
63	p3f3q20_b	Num	8	20. Pulmonary artery saturation
64	p3f3q21_a__1	Num	8	21. Pulmonary vascular resistance: NA
65	p3f3q21_b	Num	8	21. Pulmonary vascular resistance
66	p3f3q22_a__1	Num	8	22. Pulmonary capillary wedge pressure (PCWP or PAWP): NA
67	p3f3q22_b	Num	8	22. Pulmonary capillary wedge pressure (PCWP or PAWP)
68	p3f3q23_a__1	Num	8	23. Cardiac output and index: NA
69	p3f3q23_b	Num	8	21. Cardiac output and index

Data Set Name: *scdregistry_fu2renalform.sas7bdat*

Num	Variable	Type	Len	Label
1	newid	Char	8	Random ID
2	p3f5q00	Num	8	DATE FORM COMPLETED
3	p3f5q01_a2	Num	8	1a. Albuminuria: When did it start (date)?
4	p3f5q01_a	Num	8	1a. Albuminuria: When did it start ?
5	p3f5q01_b2	Num	8	1b. Albuminuria: Date of most recent measurement
6	p3f5q01_b	Num	8	1b. Albuminuria: Date most recent unk/ NA
7	p3f5q01_c	Num	8	1c. Albuminuria: Type of measurement (check one)
8	p3f5q01_d	Num	8	1d. Albuminuria: Spot urine sample (milligram albumin per liter of urine)
9	p3f5q01_e	Num	8	1e. Albuminuria: Spot urine albumin/ creatinine ratio
10	p3f5q01_e2	Num	8	Albuminuria: Unit for Spot urine
11	p3f5q02_a2	Num	8	2a. Proteinuria: When did it start (date)?
12	p3f5q02_a	Num	8	2a. Proteinuria: When did it start?
13	p3f5q02_b2	Num	8	2b. Proteinuria: Date of most recent measurement
14	p3f5q02_b	Num	8	2b. Proteinuria: Date most recent unk/ NA
15	p3f5q02_c	Num	8	2c. Proteinuria: Type of measurement (check one)
16	p3f5q02_d	Num	8	2d. Proteinuria: Spot urine sample (milligram protein per liter of urine)
17	p3f5q02_e	Num	8	2e. Proteinuria: Spot urine protein/creatinine ratio
18	p3f5q02_e2	Num	8	2e. Proteinuria: Unit for Spot urine
19	p3f5q03a_2	Num	8	3a. eGFR <60: When did it start?
20	p3f5q03a	Num	8	3a. eGFR <60: When did it start?
21	p3f5q03b_2	Num	8	3b. eGFR <60: Date of most recent measurement
22	p3f5q03b	Num	8	3b. eGFR <60: Date most recent unk/ NA
23	p3f5q04a	Num	8	4a. History of acute kidney injury (AKI*)
24	p3f5q04b	Num	8	4b. History of >1 episode of AKI*
25	p3f5q04c	Num	8	4c. Hemodialysis
26	p3f5q04d	Num	8	4d. Peritoneal dialysis
27	p3f5q04e	Num	8	4e. Kidney disease/ESRD
28	p3f5q04e_b	Num	8	4e2.Date of Kidney disease/ERSD
29	p3f5q04e_a	Num	8	4e2.Date of Kidney disease/ERSD
30	p3f5q04f	Num	8	4f. Kidney transplant
31	p3f5q04f_b	Num	8	4f2.Date of Kidney transplant
32	p3f5q04f_a__1	Num	8	4f2.Date of Kidney transplant Unk/NA
33	p3f5q04f_c	Num	8	4f3. Kidney transplant Rejection?

Data Set Name: *scdregistry_fu3ptsurvey.sas7bdat*

Num	Variable	Type	Len	Label
1	p3fl_opt_out_v3__1	Num	8	The patient has opted out of taking this survey
2	p3flq00_v3	Num	8	What is today's date?
3	p3flq01_v3	Num	8	1. Do you take pain medicine every day for your sickle cell disease?
4	p3flq02_v3__1	Num	8	2. What pain medicines do you currently take for your sickle cell disease? Dont take pain medicines.
5	p3flq03_v3	Num	8	3. In the past 12 months, how many sickle cell pain attacks (crises) did you have?
6	p3flq04_v3	Num	8	4. When was your last pain attack (crisis)?
7	p3flq05_v3	Num	8	5. 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.
8	p3flq06_v3	Num	8	6. How much did your last pain attack (crisis) interfere with your life?
9	p3flq07_v3	Num	8	7. About how long did your most recent pain attack (crisis) last?
10	p3flq08a_v3	Num	8	8a. How often did you have very severe pain?
11	p3flq08b_v3	Num	8	8b. How often did you have pain so bad that it was hard to finish what you were doing?
12	p3flq09a_v3	Num	8	9a. How often did you have very severe pain?
13	p3flq09b_v3	Num	8	9b. How often did you have pain so bad that it was hard to finish what you were doing?
14	p3flq10a_v3	Num	8	10a. Did your pain feel like pins and needles?
15	p3flq10b_v3	Num	8	10b. Did your pain feel sore?
16	p3flq11_v3	Num	8	11. Would you say that your pain management plan is...
17	p3flq12_v3	Num	8	12. Do you get regular blood transfusions for your sickle cell disease?
18	p3flq13_v3	Num	8	13. In the past 12 months, how many units (pints) of blood have you received?
19	p3flq14_v3	Num	8	14. Are you currently on iron chelation treatment (e.g., Desferal, Exjade, Jadenu, deferasirox, Ferriprox, deferiprone, phlebotomy?)
20	p3flq15_v3	Num	8	15. In the past 12 months, has your spleen been removed?
21	p3flq16a_v3	Num	8	16a. In the past 12 months, have you been newly diagnosed with Lung problems such as pneumonia or acute chest syndrome
22	p3flq16b_v3	Num	8	16b. In the past 12 months, have you been newly diagnosed with Kidney damage
23	p3flq16c_v3	Num	8	16c. In the past 12 months, have you been newly diagnosed with Eye damage called retinopathy
24	p3flq16d_v3	Num	8	16d. In the past 12 months, have you been newly diagnosed with Damage to your hip or shoulder due to sickle cell disease
25	p3flq16e_v3	Num	8	16e. In the past 12 months, have you been newly diagnosed with High blood pressure in your lungs (also called pulmonary hypertension)
26	p3flq16f_v3	Num	8	16f. In the past 12 months, have you been newly diagnosed with Heart failure
27	p3flq16g_v3	Num	8	16g. In the past 12 months, have you been newly diagnosed with Blood clots in your legs or arms or that went to your lung
28	p3flq16h_v3	Num	8	16h. In the past 12 months, have you been newly diagnosed with A stroke
29	p3flq16i_v3	Num	8	16i. In the past 12 months, have you been newly diagnosed with Asthma
30	p3flq16j_v3	Num	8	16j. In the past 12 months, have you been newly diagnosed with Diabetes
31	p3flq16k_v3	Num	8	16k. In the past 12 months, have you been newly diagnosed with Liver problems such as hepatitis, iron overload, or cirrhosis

Num	Variable	Type	Len	Label
32	p3flq16l_v3	Num	8	16l. In the past 12 months, have you been newly diagnosed with Skin ulcers
33	p3flq17_v3	Num	8	19. In the past 12 months, have you taken hydroxyurea?
34	p3flq18_v3	Num	8	20. Are you currently taking hydroxyurea?
35	p3flq19_v3	Num	8	21. In the past 12 months, what is the reason you discontinued or stopped taking hydroxyurea?
36	p3flq20_v3	Num	8	22. How many days did you take hydroxyurea in the PAST WEEK?
37	p3flq21_v3__1	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Hair loss/thinning
38	p3flq21_v3__2	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Nail blackening or discoloration
39	p3flq21_v3__3	Num	8	23. 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)
40	p3flq21_v3__4	Num	8	23. 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
41	p3flq21_v3__5	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Nausea/vomiting
42	p3flq21_v3__6	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Skin ulcers
43	p3flq21_v3__7	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Weight gain
44	p3flq21_v3__8	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Headaches or dizziness
45	p3flq21_v3__9	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Fatigue/drowsiness
46	p3flq21_v3__10	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? No side effects
47	p3flq22_v3__1	Num	8	24. 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
48	p3flq22_v3__2	Num	8	24. 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
49	p3flq22_v3__3	Num	8	24. 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
50	p3flq22_v3__4	Num	8	24. 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
51	p3flq22_v3__5	Num	8	24. 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
52	p3flq22_v3__6	Num	8	24. 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
53	p3flq22_v3__7	Num	8	24. 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
54	p3flq22_v3__8	Num	8	24. 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
55	p3flq22_v3__9	Num	8	24. 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

Num	Variable	Type	Len	Label
56	p3flq22_v3__97	Num	8	24. 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
57	p3flq23_v3	Num	8	25. In the past 12 months, have you taken the drug called Endari (l-glutamine)?
58	p3flq24_v3	Num	8	26. Are you currently taking Endari?
59	p3flq25_v3	Num	8	27. In the past 12 months, what is the reason you discontinued or stopped taking Endari?
60	p3flq26_v3	Num	8	28. How many days did you take Endari in the PAST WEEK?
61	p3flq27_v3__1	Num	8	29. In the last 12 months, what side effects have you experienced while you were taking Endari? No side effects
62	p3flq27_v3__2	Num	8	29. In the last 12 months, what side effects have you experienced while you were taking Endari? Nausea/vomiting
63	p3flq27_v3__3	Num	8	29. In the last 12 months, what side effects have you experienced while you were taking Endari? Stomach pain
64	p3flq27_v3__4	Num	8	29. In the last 12 months, what side effects have you experienced while you were taking Endari? Cough
65	p3flq27_v3__5	Num	8	29. In the last 12 months, what side effects have you experienced while you were taking Endari? Headaches or dizziness
66	p3flq27_v3__6	Num	8	29. In the last 12 months, what side effects have you experienced while you were taking Endari? Other not listed above
67	p3flq30_v3f4	Num	8	30. In the past 12 months, have you taken the drug called Adakveo (crizanlizumab)?
68	p3flq31_v3f4	Num	8	31. Are you currently taking Adakveo?
69	p3flq32_v3f4	Num	8	32. In the past 12 months, what is the reason you discontinued or stopped taking Adakveo?
70	p3flq33_v3f4	Num	8	33. How many infusions of Adakveo have you missed or rescheduled in the PAST 6 MONTHS?
71	p3flq34_v3f4__1	Num	8	34. In the last 12 months, what side effects have you experienced while you were taking Adakveo? No side effects
72	p3flq34_v3f4__2	Num	8	34. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Fever
73	p3flq34_v3f4__3	Num	8	34. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Chills or shivering
74	p3flq34_v3f4__4	Num	8	34. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Nausea
75	p3flq34_v3f4__5	Num	8	34. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Vomiting
76	p3flq34_v3f4__6	Num	8	34. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Shortness of breath
77	p3flq34_v3f4__7	Num	8	34. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Muscle aches (myalias)
78	p3flq34_v3f4__8	Num	8	34. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Other not listed above
79	p3flq35_v3f4	Num	8	35. In the past 12 months, have you taken the drug called Oxbryta (voxelotor)?
80	p3flq36_v3f4	Num	8	36. Are you currently taking Oxbryta?
81	p3flq37_v3f4	Num	8	37. In the past 12 months, what is the reason you discontinued or stopped taking Oxbryta?
82	p3flq38_v3f4	Num	8	38. How many days did you take Oxbryta in the PAST WEEK?
83	p3flq39_v3f4__1	Num	8	39. In the last 12 months, what side effects have you experienced while you were taking Oxbryta? No side effects

Num	Variable	Type	Len	Label
84	p3flq39_v3f4__2	Num	8	39. In the last 12 months, what side effects have you experienced while you were taking Oxbryta? Rash or hives
85	p3flq39_v3f4__3	Num	8	39. In the last 12 months, what side effects have you experienced while you were taking Oxbryta? Headache
86	p3flq39_v3f4__4	Num	8	39. In the last 12 months, what side effects have you experienced while you were taking Oxbryta? Nausea
87	p3flq39_v3f4__5	Num	8	39. In the last 12 months, what side effects have you experienced while you were taking Oxbryta? Abdominal pain
88	p3flq39_v3f4__6	Num	8	39. In the last 12 months, what side effects have you experienced while you were taking Oxbryta? Loose stools
89	p3flq39_v3f4__7	Num	8	39. In the last 12 months, what side effects have you experienced while you were taking Oxbryta? Other not listed above
90	p3flq29_v3	Num	8	41. Are you taking any medications for high blood pressure (hypertension) or for your heart?
91	p3flq30_v3	Num	8	42. Are you taking any other type of medication that we did not already ask about?
92	p3flq31_v3	Num	8	43. Are you currently participating in a study where you are taking a medicine for sickle cell?
93	p3flq32a_v3	Num	8	a. How often did you stay up most of the night because you could not fall asleep?
94	p3flq32b_v3	Num	8	b. How often did you have a lot of trouble falling asleep?
95	p3flq33a_v3	Num	8	33av3. I have someone who will listen to me when I need to talk
96	p3flq33b_v3	Num	8	33bv3. I have someone to confide in or talk to about myself or my problems
97	p3flq33c_v3	Num	8	33cv3. I have someone who makes me feel appreciated
98	p3flq33d_v3	Num	8	33dv3. I have someone to talk with when I have a bad day
99	p3flq34a_v3	Num	8	34av3. I felt worthless.
100	p3flq34b_v3	Num	8	34bv3. I felt helpless.
101	p3flq34c_v3	Num	8	34cv3. I felt depressed.
102	p3flq34d_v3	Num	8	34dv3. I felt hopeless.
103	p3flq34e_v3	Num	8	34ev3. How often did you feel completely hopeless because of your health?
104	p3flq34f_v3	Num	8	34fv3. How often were you very worried about needing to go to the hospital?
105	p3flq34g_v3	Num	8	34gv3. I felt tired.
106	p3flq35a_v3	Num	8	35av3. I felt fearful
107	p3flq35b_v3	Num	8	35bv3. I found it hard to focus on anything other than my anxiety
108	p3flq35c_v3	Num	8	35cv3. My worries overwhelmed me
109	p3flq35d_v3	Num	8	35dv3. I felt uneasy
110	p3flq36a_v3	Num	8	36av3. I had to read something several times to understand it.
111	p3flq36b_v3	Num	8	36bv3. My thinking was slow.
112	p3flq36c_v3	Num	8	36cv3. I had to work really hard to pay attention or I would make a mistake.
113	p3flq36d_v3	Num	8	36dv3. I had trouble concentrating.
114	p3flq37a_v3	Num	8	37av3. Reading and following complex instructions (e.g., directions for a new medication)?
115	p3flq37b_v3	Num	8	37bv3. Planning for and keeping appointments that are not part of your weekly routine (e.g., therapy or doctor appointment, social gathering with friends/family)?
116	p3flq37c_v3	Num	8	37cv3. Managing your time to do most of your daily activities?
117	p3flq37d_v3	Num	8	37dv3. Learning new tasks or instructions?

Num	Variable	Type	Len	Label
118	p3flq38a_v3	Num	8	38av3. How much did you rely on others to take care of you because of your health?
119	p3flq38b_v3	Num	8	38bv3. How much did your health make it hard for you to do things with your friends?
120	p3flq39a_v3	Num	8	38cv3. I feel alone and apart from others
121	p3flq39b_v3	Num	8	38dv3. I feel left out
122	p3flq39c_v3	Num	8	39av3. I feel that I am no longer close to anyone
123	p3flq39d_v3	Num	8	39bv3. I feel alone
124	p3flq39e_v3	Num	8	39cv3. I feel lonely
125	p3flq39f_v3	Num	8	39dv3. I feel isolated from others
126	p3flq40a_v3	Num	8	40av3. I tend to bounce back quickly after hard times
127	p3flq40b_v3	Num	8	40bv3. I have a hard time making it through stressful events
128	p3flq40c_v3	Num	8	40cv3. It does not take me long to recover from a stressful event
129	p3flq40d_v3	Num	8	40dv3. It is hard for me to snap back when something bad happens
130	p3flq40e_v3	Num	8	40ev3. I usually come through difficult times with little trouble
131	p3flq40f_v3	Num	8	40fv3. I tend to take a long time to get over set-backs in my life
132	p3flq41_1a_v3	Num	8	41.1a. In general, how would you rate your physical health?
133	p3flq41_2b_v3	Num	8	41.2b. To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?
134	p3flq42_v3	Num	8	54. How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?
135	p3flq43a_v3	Num	8	43av3. I can follow directions when my doctor changes my medications.
136	p3flq43b_v3	Num	8	43bv3. I can take my medication when there is a change in my usual day (unexpected things happen).
137	p3flq43c_v3	Num	8	43cv3. I can manage my medication without help.
138	p3flq43d_v3	Num	8	43dv3. I can list my medications, including the doses and schedule.
139	p3flq44_v3	Num	8	56. 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?
140	p3flq45_v3__1	Num	8	57. 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
141	p3flq45_v3__2	Num	8	57. 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 wouldnt accept your health insurance
142	p3flq45_v3__3	Num	8	57. 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 wouldnt pay for the treatment
143	p3flq45_v3__4	Num	8	57. 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 couldnt get an appointment soon enough
144	p3flq45_v3__5	Num	8	57. 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 couldnt get there when the doctors office or clinic was open
145	p3flq45_v3__6	Num	8	57. 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 doctors office or clinic from your house or work

Num	Variable	Type	Len	Label
146	p3flq45_v3__7	Num	8	57. 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 couldnt get through on the telephone
147	p3flq45_v3__8	Num	8	57. 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
148	p3flq45_v3__9	Num	8	57. 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 didnt think the problem was serious enough
149	p3flq45_v3__10	Num	8	57. 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
150	p3flq45_v3__11	Num	8	57. 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 doctors office or clinic dont speak the same language I do
151	p3flq45_v3__12	Num	8	57. 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
152	p3flq45_v3__97	Num	8	57. 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
153	p3flq46_v3	Num	8	58. How hard is it for you to pay for the very basics like food, housing, medical care, and heating?
154	p3flq47_v3	Num	8	59. Did you lose your health insurance in the past year?
155	p3flq48_a1_v3	Num	8	48av3. Experienced discrimination because of your race, ethnicity, or color in any of these situation: at school?
156	p3flq48_a2_v3	Num	8	48av3. How many times did this happen in the past 12 months?
157	p3flq48_b1_v3	Num	8	48bv3. Experienced discrimination because of your race, ethnicity, or color in any of these situation: getting hired or getting a job?
158	p3flq48_b2_v3	Num	8	48bv3. How many times did this happen in the past 12 months?
159	p3flq48_c1_v3	Num	8	48cv3. Experienced discrimination because of your race, ethnicity, or color in any of these situation: at work?
160	p3flq48_c2_v3	Num	8	48cv3. How many times did this happen in the past 12 months?
161	p3flq48_d1_v3	Num	8	48dv3. Experienced discrimination because of your race, ethnicity, or color in any of these situation: getting housing?
162	p3flq48_d2_v3	Num	8	48dv3. How many times did this happen in the past 12 months?
163	p3flq48_e1_v3	Num	8	48ev3. Experienced discrimination because of your race, ethnicity, or color in any of these situation: getting medical care?
164	p3flq48_e2_v3	Num	8	48ev3. How many times did this happen in the past 12 months?
165	p3flq48_f1_v3	Num	8	48fv3. Experienced discrimination because of your race, ethnicity, or color in any of these situation: getting service in a store or restaurant?
166	p3flq48_f2_v3	Num	8	48fv3. How many times did this happen in the past 12 months?
167	p3flq48_g1_v3	Num	8	48gv3. Experienced discrimination because of your race, ethnicity, or color in any of these situation: getting credit, bank loans, or a mortgage?
168	p3flq48_g2_v3	Num	8	48gv3. How many times did this happen in the past 12 months?
169	p3flq48_h1_v3	Num	8	48hv3. Experienced discrimination because of your race, ethnicity, or color in any of these situation: on the street or in a public setting?

Num	Variable	Type	Len	Label
170	p3flq48_h2_v3	Num	8	48hv3. How many times did this happen in the past 12 months?
171	p3flq48_i1_v3	Num	8	48iv3. Experienced discrimination because of your race, ethnicity, or color in any of these situation: from the police or in the courts?
172	p3flq48_i2_v3	Num	8	48iv3. How many times did this happen in the past 12 months?
173	newid	Char	8	Random ID
174	painmedscount	Num	8	Number of pain medications currently taking (Q2)
175	othermedscount	Num	8	Number of other medications currently taking (Q28)

Data Set Name: *scdregistry_fu4ptsurvey.sas7bdat*

Num	Variable	Type	Len	Label
1	p3fl_opt_out_v3v4__1	Num	8	The patient has opted out of taking this survey (choice=)
2	p3flq00_v3v4	Num	8	What is today's date?
3	p3flq01_v3v4	Num	8	1. Do you take pain medicine every day for your sickle cell disease?
4	p3flq02_v3v4__1	Num	8	2. What pain medicines do you currently take for your sickle cell disease? Dont take pain medicines.
5	p3flq03_v3v4	Num	8	3. In the past 12 months, how many sickle cell pain attacks (crises) did you have?
6	p3flq04_v3v4	Num	8	4. When was your last pain attack (crisis)?
7	p3flq05_v3v4	Num	8	5. 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.
8	p3flq06_v3v4	Num	8	6. How much did your last pain attack (crisis) interfere with your life?
9	p3flq07_v3v4	Num	8	7. About how long did your most recent pain attack (crisis) last?
10	p3flq08a_v3v4	Num	8	8a. How often did you have very severe pain?
11	p3flq08b_v3v4	Num	8	8b. How often did you have pain so bad that it was hard to finish what you were doing?
12	p3flq09a_v3v4	Num	8	9a. How often did you have very severe pain?
13	p3flq09b_v3v4	Num	8	9b. How often did you have pain so bad that it was hard to finish what you were doing?
14	p3flq10a_v3v4	Num	8	10a. Did your pain feel like pins and needles?
15	p3flq10b_v3v4	Num	8	10b. Did your pain feel sore?
16	p3flq11_v3v4	Num	8	11. Would you say that your pain management plan is....
17	p3flq12_v3v4	Num	8	12. Do you get regular blood transfusions for your sickle cell disease?
18	p3flq13_v3v4	Num	8	13. In the past 12 months, how many units (pints) of blood have you received?
19	p3flq14_v3v4	Num	8	14. Are you currently on iron chelation treatment (e.g., Desferal, Exjade, Jadenu, deferasirox, Ferriprox, deferiprone, phlebotomy?)
20	p3flq15_v3v4	Num	8	15. In the past 12 months, has your spleen been removed?
21	p3flq16a_v3v4	Num	8	16a. In the past 12 months, have you been newly diagnosed with Lung problems such as pneumonia or acute chest syndrome
22	p3flq16b_v3v4	Num	8	16b. In the past 12 months, have you been newly diagnosed with Kidney damage
23	p3flq16c_v3v4	Num	8	16c. In the past 12 months, have you been newly diagnosed with Eye damage called retinopathy
24	p3flq16d_v3v4	Num	8	16d. In the past 12 months, have you been newly diagnosed with Damage to your hip or shoulder due to sickle cell disease
25	p3flq16e_v3v4	Num	8	16e. In the past 12 months, have you been newly diagnosed with High blood pressure in your lungs (also called pulmonary hypertension)
26	p3flq16f_v3v4	Num	8	16f. In the past 12 months, have you been newly diagnosed with Heart failure
27	p3flq16g_v3v4	Num	8	16g. In the past 12 months, have you been newly diagnosed with Blood clots in your legs or arms or that went to your lung
28	p3flq16h_v3v4	Num	8	16h. In the past 12 months, have you been newly diagnosed with A stroke
29	p3flq16i_v3v4	Num	8	16i. In the past 12 months, have you been newly diagnosed with Asthma
30	p3flq16j_v3v4	Num	8	16j. In the past 12 months, have you been newly diagnosed with Diabetes
31	p3flq16k_v3v4	Num	8	16k. In the past 12 months, have you been newly diagnosed with Liver problems such as hepatitis, iron overload, or cirrhosis

Num	Variable	Type	Len	Label
32	p3flq16l_v3v4	Num	8	16l. In the past 12 months, have you been newly diagnosed with Skin ulcers
33	p3flq17_v3v4	Num	8	19. In the past 12 months, have you taken hydroxyurea?
34	p3flq18_v3v4	Num	8	20. Are you currently taking hydroxyurea?
35	p3flq19_v3v4	Num	8	21. In the past 12 months, what is the reason you discontinued or stopped taking hydroxyurea?
36	p3flq20_v3v4	Num	8	22. How many days did you take hydroxyurea in the PAST WEEK?
37	p3flq21_v3v4__1	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Hair loss/thinning
38	p3flq21_v3v4__2	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Nail blackening or discoloration
39	p3flq21_v3v4__3	Num	8	23. 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)
40	p3flq21_v3v4__4	Num	8	23. 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
41	p3flq21_v3v4__5	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Nausea/vomiting
42	p3flq21_v3v4__6	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Skin ulcers
43	p3flq21_v3v4__7	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Weight gain
44	p3flq21_v3v4__8	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Headaches or dizziness
45	p3flq21_v3v4__9	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Fatigue/drowsiness
46	p3flq21_v3v4__10	Num	8	23. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? No side effects
47	p3flq22_v3v4__1	Num	8	24. 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
48	p3flq22_v3v4__2	Num	8	24. 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
49	p3flq22_v3v4__3	Num	8	24. 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
50	p3flq22_v3v4__4	Num	8	24. 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
51	p3flq22_v3v4__5	Num	8	24. 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
52	p3flq22_v3v4__6	Num	8	24. 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
53	p3flq22_v3v4__7	Num	8	24. 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
54	p3flq22_v3v4__8	Num	8	24. 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
55	p3flq22_v3v4__9	Num	8	24. 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

Num	Variable	Type	Len	Label
56	p3flq22_v3v4__97	Num	8	24. 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
57	p3flq23_v3v4	Num	8	25. In the past 12 months, have you taken the drug called Endari (l-glutamine)?
58	p3flq27_v3v4__1	Num	8	29. In the last 12 months, what side effects have you experienced while you were taking Endari? No side effects
59	p3flq27_v3v4__2	Num	8	29. In the last 12 months, what side effects have you experienced while you were taking Endari? Nausea/vomiting
60	p3flq27_v3v4__3	Num	8	29. In the last 12 months, what side effects have you experienced while you were taking Endari? Stomach pain
61	p3flq27_v3v4__4	Num	8	29. In the last 12 months, what side effects have you experienced while you were taking Endari? Cough
62	p3flq27_v3v4__5	Num	8	29. In the last 12 months, what side effects have you experienced while you were taking Endari? Headaches or dizziness
63	p3flq27_v3v4__6	Num	8	29. In the last 12 months, what side effects have you experienced while you were taking Endari? Other not listed above
64	p3flq30_v4	Num	8	30. In the past 12 months, have you taken the drug called Adakveo (crizanlizumab)?
65	p3flq31_v4	Num	8	31. Are you currently taking Adakveo?
66	p3flq33_v4	Num	8	33. How many infusions of Adakveo have you missed or rescheduled in the PAST 6 MONTHS?
67	p3flq34_v4__1	Num	8	34. In the last 12 months, what side effects have you experienced while you were taking Adakveo? No side effects
68	p3flq34_v4__2	Num	8	34. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Fever
69	p3flq34_v4__3	Num	8	34. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Chills or shivering
70	p3flq34_v4__4	Num	8	34. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Nausea
71	p3flq34_v4__5	Num	8	34. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Vomiting
72	p3flq34_v4__6	Num	8	34. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Shortness of breath
73	p3flq34_v4__7	Num	8	34. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Muscle aches (myalias)
74	p3flq34_v4__8	Num	8	34. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Other not listed above
75	p3flq35_v4	Num	8	35. In the past 12 months, have you taken the drug called Oxbryta (voxelotor)?
76	p3flq36_v4	Num	8	36. Are you currently taking Oxbryta?
77	p3flq37_v4	Num	8	37. In the past 12 months, what is the reason you discontinued or stopped taking Oxbryta? Please select one from the list below.
78	p3flq38_v4	Num	8	38. How many days did you take Oxbryta in the PAST WEEK?
79	p3flq39_v4__1	Num	8	39. In the last 12 months, what side effects have you experienced while you were taking Oxbryta? No side effects
80	p3flq39_v4__2	Num	8	39. In the last 12 months, what side effects have you experienced while you were taking Oxbryta? Rash or hives
81	p3flq39_v4__3	Num	8	39. In the last 12 months, what side effects have you experienced while you were taking Oxbryta? Headache

Num	Variable	Type	Len	Label
82	p3flq39_v4__4	Num	8	39. In the last 12 months, what side effects have you experienced while you were taking Oxbryta? Nausea
83	p3flq39_v4__5	Num	8	39. In the last 12 months, what side effects have you experienced while you were taking Oxbryta? Abdominal pain
84	p3flq39_v4__6	Num	8	39. In the last 12 months, what side effects have you experienced while you were taking Oxbryta? Loose stools
85	p3flq39_v4__7	Num	8	39. In the last 12 months, what side effects have you experienced while you were taking Oxbryta? Other not listed above
86	p3flq29_v3v4	Num	8	41. Are you taking any medications for high blood pressure (hypertension) or for your heart?
87	p3flq30_v3v4	Num	8	42. Are you taking any other type of medication that we did not already ask about?
88	p3flq31_v3v4	Num	8	43. Are you currently participating in a study where you are taking a medicine for sickle cell?
89	p3flq32a_v3v4	Num	8	a. How often did you stay up most of the night because you could not fall asleep?
90	p3flq32b_v3v4	Num	8	b. How often did you have a lot of trouble falling asleep?
91	p3flq33a_v3v4	Num	8	33av3. I have someone who will listen to me when I need to talk
92	p3flq33b_v3v4	Num	8	33bv3. I have someone to confide in or talk to about myself or my problems
93	p3flq33c_v3v4	Num	8	33cv3. I have someone who makes me feel appreciated
94	p3flq33d_v3v4	Num	8	33dv3. I have someone to talk with when I have a bad day
95	p3flq34a_v3v4	Num	8	34av3. I felt worthless.
96	p3flq34b_v3v4	Num	8	34bv3. I felt helpless.
97	p3flq34c_v3v4	Num	8	34cv3. I felt depressed.
98	p3flq34d_v3v4	Num	8	34dv3. I felt hopeless.
99	p3flq34e_v3v4	Num	8	34ev3. How often did you feel completely hopeless because of your health?
100	p3flq34f_v3v4	Num	8	34fv3. How often were you very worried about needing to go to the hospital?
101	p3flq34g_v3v4	Num	8	34gv3. I felt tired.
102	p3flq35a_v3v4	Num	8	35av3. I felt fearful
103	p3flq35b_v3v4	Num	8	35bv3. I found it hard to focus on anything other than my anxiety
104	p3flq35c_v3v4	Num	8	35cv3. My worries overwhelmed me
105	p3flq35d_v3v4	Num	8	35dv3. I felt uneasy
106	p3flq36a_v3v4	Num	8	36av3. I had to read something several times to understand it.
107	p3flq36b_v3v4	Num	8	36bv3. My thinking was slow.
108	p3flq36c_v3v4	Num	8	36cv3. I had to work really hard to pay attention or I would make a mistake.
109	p3flq36d_v3v4	Num	8	36dv3. I had trouble concentrating.
110	p3flq37a_v3v4	Num	8	37av3. Reading and following complex instructions (e.g., directions for a new medication)?
111	p3flq37b_v3v4	Num	8	37bv3. Planning for and keeping appointments that are not part of your weekly routine (e.g., therapy or doctor appointment, social gathering with friends/family)?
112	p3flq37c_v3v4	Num	8	37cv3. Managing your time to do most of your daily activities?
113	p3flq37d_v3v4	Num	8	37dv3. Learning new tasks or instructions?
114	p3flq38a_v3v4	Num	8	38av3. How much did you rely on others to take care of you because of your health?
115	p3flq38b_v3v4	Num	8	38bv3. How much did your health make it hard for you to do things with your friends?

Num	Variable	Type	Len	Label
116	p3flq39a_v3v4	Num	8	38cv3. I feel alone and apart from others
117	p3flq39b_v3v4	Num	8	38dv3. I feel left out
118	p3flq39c_v3v4	Num	8	39av3. I feel that I am no longer close to anyone
119	p3flq39d_v3v4	Num	8	39bv3. I feel alone
120	p3flq39e_v3v4	Num	8	39cv3. I feel lonely
121	p3flq39f_v3v4	Num	8	39dv3. I feel isolated from others
122	p3flq40a_v3v4	Num	8	40av3. I tend to bounce back quickly after hard times
123	p3flq40b_v3v4	Num	8	40bv3. I have a hard time making it through stressful events
124	p3flq40c_v3v4	Num	8	40cv3. It does not take me long to recover from a stressful event
125	p3flq40d_v3v4	Num	8	40dv3. It is hard for me to snap back when something bad happens
126	p3flq40e_v3v4	Num	8	40ev3. I usually come through difficult times with little trouble
127	p3flq40f_v3v4	Num	8	40fv3. I tend to take a long time to get over set-backs in my life
128	p3flq41_1a_v3v4	Num	8	41.1a. In general, how would you rate your physical health?
129	p3flq41_2b_v3v4	Num	8	41.2b. To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?
130	p3flq42_v3v4	Num	8	54. How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?
131	p3flq43a_v3v4	Num	8	43av3. I can follow directions when my doctor changes my medications.
132	p3flq43b_v3v4	Num	8	43bv3. I can take my medication when there is a change in my usual day (unexpected things happen).
133	p3flq43c_v3v4	Num	8	43cv3. I can manage my medication without help.
134	p3flq43d_v3v4	Num	8	43dv3. I can list my medications, including the doses and schedule.
135	p3flq44_v3v4	Num	8	56. 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?
136	p3flq45_v3v4__1	Num	8	57. 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
137	p3flq45_v3v4__2	Num	8	57. 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 wouldnt accept your health insurance
138	p3flq45_v3v4__3	Num	8	57. 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 wouldnt pay for the treatment
139	p3flq45_v3v4__4	Num	8	57. 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 couldnt get an appointment soon enough
140	p3flq45_v3v4__5	Num	8	57. 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 couldnt get there when the doctors office or clinic was open
141	p3flq45_v3v4__6	Num	8	57. 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 doctors office or clinic from your house or work
142	p3flq45_v3v4__7	Num	8	57. 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 couldnt get through on the telephone

Num	Variable	Type	Len	Label
143	p3flq45_v3v4__8	Num	8	57. 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
144	p3flq45_v3v4__9	Num	8	57. 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 didnt think the problem was serious enough
145	p3flq45_v3v4__10	Num	8	57. 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
146	p3flq45_v3v4__11	Num	8	57. 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 doctors office or clinic dont speak the same language I do
147	p3flq45_v3v4__12	Num	8	57. 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
148	p3flq45_v3v4__97	Num	8	57. 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
149	p3flq46_v3v4	Num	8	58. How hard is it for you to pay for the very basics like food, housing, medical care, and heating?
150	p3flq47_v3v4	Num	8	59. Did you lose your health insurance in the past year?
151	p3flq48_a1_v3v4	Num	8	48av3. Experienced discrimination because of your race, ethnicity, or color in any of these situation: at school?
152	p3flq48_b1_v3v4	Num	8	48bv3. Experienced discrimination because of your race, ethnicity, or color in any of these situation: getting hired or getting a job?
153	p3flq48_c1_v3v4	Num	8	48cv3. Experienced discrimination because of your race, ethnicity, or color in any of these situation: at work?
154	p3flq48_d1_v3v4	Num	8	48dv3. Experienced discrimination because of your race, ethnicity, or color in any of these situation: getting housing?
155	p3flq48_e1_v3v4	Num	8	48ev3. Experienced discrimination because of your race, ethnicity, or color in any of these situation: getting medical care?
156	p3flq48_f1_v3v4	Num	8	48fv3. Experienced discrimination because of your race, ethnicity, or color in any of these situation: getting service in a store or restaurant?
157	p3flq48_f2_v3v4	Num	8	48fv3. How many times did this happen in the past 12 months?
158	p3flq48_g1_v3v4	Num	8	48gv3. Experienced discrimination because of your race, ethnicity, or color in any of these situation: getting credit, bank loans, or a mortgage?
159	p3flq48_g2_v3v4	Num	8	48gv3. How many times did this happen in the past 12 months?
160	p3flq48_h1_v3v4	Num	8	48hv3. Experienced discrimination because of your race, ethnicity, or color in any of these situation: on the street or in a public setting?
161	p3flq48_i1_v3v4	Num	8	48iv3. Experienced discrimination because of your race, ethnicity, or color in any of these situation: from the police or in the courts?
162	newid	Char	8	Random ID
163	painmedscount	Num	8	Number of pain medications currently taking (Q2)
164	othermedscount	Num	8	Number of other medications currently taking (Q40)

Data Set Name: *scdregistry_labform.sas7bdat*

Num	Variable	Type	Len	Label
1	p1f2q0__1	Num	8	FORM COMPLETE, LABRATORY RECORDS NOT AVAILABLE
2	p1f2q1__1	Num	8	1. Nucleated RBC (choice=NA)
3	p1f2q1_1	Num	8	1. Nucleated RBC Test results
4	p1f2q1_1b	Num	8	1. Nucleated RBC Unit
5	p1f2q1_2	Num	8	1. Nucleated RBC Date of Most Recent
6	p1f2q2__1	Num	8	2. White Blood Cells (choice=NA)
7	p1f2q2_1	Num	8	2. White Blood Cells Test results
8	p1f2q2_2	Num	8	2. White Blood Cells Date of Most Recent
9	p1f2q3__1	Num	8	3. RBC (choice=NA)
10	p1f2q3_1	Num	8	3. RBC Test results
11	p1f2q3_2	Num	8	3. RBC Date of Most Recent
12	p1f2q4__1	Num	8	4. Hemoglobin (choice=NA)
13	p1f2q4_1	Num	8	4. Hemoglobin Test results
14	p1f2q4_2	Num	8	4. Hemoglobin Date of Most Recent
15	p1f2q5__1	Num	8	5. Hematocrit (choice=NA)
16	p1f2q5_1	Num	8	5. Hematocrit Test results
17	p1f2q5_2	Num	8	5. Hematocrit Date of Most Recent
18	p1f2q6__1	Num	8	6. MCV (choice=NA)
19	p1f2q6_1	Num	8	6. MCV Test results
20	p1f2q6_2	Num	8	6. MCV Date of Most Recent
21	p1f2q7__1	Num	8	7. MCH (choice=NA)
22	p1f2q7_1	Num	8	7. MCH Test results
23	p1f2q7_2	Num	8	7. MCH Date of Most Recent
24	p1f2q8__1	Num	8	8. MCHC (choice=NA)
25	p1f2q8_1	Num	8	8. MCHC Test results
26	p1f2q8_2	Num	8	8. MCHC Date of Most Recent
27	p1f2q9__1	Num	8	9. Platelets (choice=NA)
28	p1f2q9_1	Num	8	9. Platelets Test results
29	p1f2q9_2	Num	8	9. Platelets Date of Most Recent
30	p1f2q10__1	Num	8	10. Neutrophils (segmented and band together) (choice=NA)
31	p1f2q10_1	Num	8	10. Neutrophils Test results
32	p1f2q10_2	Num	8	10. Neutrophils Date of Most Recent
33	p1f2q11__1	Num	8	11. Lymphocytes (choice=NA)
34	p1f2q11_1	Num	8	11. Lymphocytes Test results
35	p1f2q11_2	Num	8	11. Lymphocytes Date of Most Recent
36	p1f2q12__1	Num	8	12. Monocytes (choice=NA)
37	p1f2q12_1	Num	8	12. Monocytes Test results

Num	Variable	Type	Len	Label
38	p1f2q12_2	Num	8	12. Monocytes Date of Most Recent
39	p1f2q13__1	Num	8	13. Reticulocytes (choice=NA)
40	p1f2q13_1	Num	8	13. Reticulocytes Test results, %
41	p1f2q13_4	Num	8	13. Reticulocytes Test results, 10^3/microliter
42	p1f2q13_3	Num	8	13. Reticulocytes Date of Most Recent
43	p1f2q14__1	Num	8	14. Serum BUN (choice=NA)
44	p1f2q14_1	Num	8	14. Serum BUN Test results
45	p1f2q14_2	Num	8	14. Serum BUN Date of Most Recent
46	p1f2q15__1	Num	8	15. Serum Creatinine (choice=NA)
47	p1f2q15_1	Num	8	15. Serum Creatinine Test results
48	p1f2q15_2	Num	8	15. Serum Creatinine Date of Most Recent
49	p1f2q16__1	Num	8	16. Estimated GFR (choice=NA)
50	p1f2q16_1	Num	8	16. Estimated GFR Test results
51	p1f2q16_2	Num	8	16. Estimated GFR Date of Most Recent
52	p1f2q17__1	Num	8	17. Estimated creatinine clearance (choice=NA)
53	p1f2q17_1	Num	8	17. Estimated creatinine clearance Test results
54	p1f2q17_2	Num	8	17. Estimated creatinine clearance Date of Most Recent
55	p1f2q18__1	Num	8	18. Total Cholesterol (choice=NA)
56	p1f2q18_1	Num	8	18. Total Cholesterol Test results
57	p1f2q18_2	Num	8	18. Total Cholesterol Date of Most Recent
58	p1f2q19__1	Num	8	19. Non-Fasting HDL (choice=NA)
59	p1f2q19_1	Num	8	19. Non-Fasting HDL Test results
60	p1f2q19_2	Num	8	19. Non-Fasting HDL Date of Most Recent
61	p1f2q20__1	Num	8	20. Fasting HDL (choice=NA)
62	p1f2q20_1	Num	8	20. Fasting HDL Test results
63	p1f2q20_2	Num	8	20. Fasting HDL Date of Most Recent
64	p1f2q21__1	Num	8	21. Non-Fasting LDL (choice=NA)
65	p1f2q21_1	Num	8	21. Non-Fasting LDL Test results
66	p1f2q21_2	Num	8	21. Non-Fasting LDL Date of Most Recent
67	p1f2q22__1	Num	8	22. Fasting LDL (choice=NA)
68	p1f2q22_1	Num	8	22. Fasting LDL Test results
69	p1f2q22_2	Num	8	22. Fasting LDL Date of Most Recent
70	p1f2q23__1	Num	8	23. Triglyceride (choice=NA)
71	p1f2q23_1	Num	8	23. Triglyceride Test results
72	p1f2q23_2	Num	8	23. Triglyceride Date of Most Recent
73	p1f2q24__1	Num	8	24. Non-Fasting Blood Glucose (choice=NA)
74	p1f2q24_1	Num	8	24. Non-Fasting Blood Glucose Test results
75	p1f2q24_2	Num	8	24. Non-Fasting Blood Glucose Date of Most Recent
76	p1f2q25__1	Num	8	25. Fasting Blood Glucose (choice=NA)

Num	Variable	Type	Len	Label
77	p1f2q25_1	Num	8	25. Fasting Blood Glucose Test results
78	p1f2q25_2	Num	8	25. Fasting Blood Glucose Date of Most Recent
79	p1f2q26__1	Num	8	26. CRP (choice=NA)
80	p1f2q26_1	Num	8	26. CRP Test results
81	p1f2q26_1a	Num	8	26. CRP Unit
82	p1f2q26_2	Num	8	26. CRP Date of Most Recent
83	p1f2q27__1	Num	8	27. Bilirubin serum, total (choice=NA)
84	p1f2q27_1	Num	8	27. Bilirubin serum, total Test results
85	p1f2q27_2	Num	8	27. Bilirubin serum, total Date of Most Recent
86	p1f2q28__1	Num	8	28. Bilirubin, serum, direct (choice=NA)
87	p1f2q28_1	Num	8	28. Bilirubin, serum, direct Test results
88	p1f2q28_2	Num	8	28. Bilirubin, serum, direct date of Most Recent
89	p1f2q29__1	Num	8	29. AST (choice=NA)
90	p1f2q29_1	Num	8	29. AST Test results
91	p1f2q29_2	Num	8	29. AST Date of Most Recent
92	p1f2q30__1	Num	8	30. ALT (choice=NA)
93	p1f2q30_1	Num	8	30. ALT (Test results
94	p1f2q30_2	Num	8	30. ALT (Date of Most Recent
95	p1f2q31__1	Num	8	31. Alkaline Phosphatase (choice=NA)
96	p1f2q31_1	Num	8	31. Alkaline Phosphatase (Test results
97	p1f2q31_2	Num	8	31. Alkaline Phosphatase (Date of Most Recent
98	p1f2q32__1	Num	8	32. Total Protein (plasma) (choice=NA)
99	p1f2q32_1	Num	8	32. Total Protein (plasma) Test results
100	p1f2q32_2	Num	8	32. Total Protein (plasma) Date of Most Recent
101	p1f2q33__1	Num	8	33. Albumin (choice=NA)
102	p1f2q33_1	Num	8	33. Albumin Test results
103	p1f2q33_2	Num	8	33. Albumin Date of Most Recent
104	p1f2q34__1	Num	8	34. LDH (serum) (choice=NA)
105	p1f2q34_1	Num	8	34. LDH (serum) Test results
106	p1f2q34_2	Num	8	34. LDH (serum) Date of Most Recent
107	p1f2q35__1	Num	8	35. NT-pro-BNP (choice=NA)
108	p1f2q35_1	Num	8	35. NT-pro-BNP Test results
109	p1f2q35_2	Num	8	35. NT-pro-BNP Date of Most Recent
110	p1f2q36__1	Num	8	36. BNP (choice=NA)
111	p1f2q36_1	Num	8	36. BNP Test results
112	p1f2q36_2	Num	8	36. BNP Date of Most Recent
113	p1f2q37__1	Num	8	37. Serum iron (choice=NA)
114	p1f2q37_1	Num	8	37. Serum iron Test results
115	p1f2q37_2	Num	8	37. Serum iron Date of Most Recent

Num	Variable	Type	Len	Label
116	p1f2q38__1	Num	8	38. Total iron binding capacity (TIBC) (choice=NA)
117	p1f2q38_1	Num	8	38. Total iron binding capacity (TIBC) Test results
118	p1f2q38_2	Num	8	38. Total iron binding capacity (TIBC) Date of Most Recent
119	p1f2q39__1	Num	8	39. Serum transferrin (choice=NA)
120	p1f2q39_1	Num	8	39. Serum transferrin Test results
121	p1f2q39_1a	Num	8	39. Serum transferrin Unit
122	p1f2q39_2	Num	8	39. Serum transferrin Date of Most Recent
123	p1f2q40__1	Num	8	40. Ferritin (choice=NA)
124	p1f2q40_1	Num	8	40. Ferritin (Test results
125	p1f2q40_2	Num	8	40. Ferritin (Date of Most Recent
126	p1f2q41__1	Num	8	41. 25-Hydroxy Vitamin D (choice=NA)
127	p1f2q41_1	Num	8	41. 25-Hydroxy Vitamin D Test results
128	p1f2q41_2	Num	8	41. 25-Hydroxy Vitamin D Date of Most Recent
129	p1f2q42__1	Num	8	42. Erythropoietin (EPO) (choice=NA)
130	p1f2q42_1	Num	8	42. Erythropoietin (EPO) Test results
131	p1f2q42_2	Num	8	42. Erythropoietin (EPO) Date of Most Recent
132	p1f2q43__1	Num	8	43. Urine albumin (choice=NA)
133	p1f2q43_1	Num	8	43. Urine albumin Test results
134	p1f2q43_1a	Num	8	43. Urine albumin Unit
135	p1f2q43_2	Num	8	43. Urine albumin Date of Most Recent
136	p1f2q44__1	Num	8	44. Urine albumin / creatinine (choice=NA)
137	p1f2q44_1	Num	8	44. Urine albumin / creatinine Test results
138	p1f2q44_2	Num	8	44. Urine albumin / creatinine Date of Most Recent
139	p1f2q45__1	Num	8	45. Urine protein (dipstick) (choice=NA)
140	p1f2q45_1	Num	8	45. Urine protein (dipstick) Test results
141	p1f2q45_2	Num	8	45. Urine protein (dipstick) Date of Most Recent
142	p1f2q46__1	Num	8	46. Urine protein/creatinine (choice=NA)
143	p1f2q46_1	Num	8	46. Urine protein/creatinine Test results
144	p1f2q46_2	Num	8	46. Urine protein/creatinine Date of Most Recent
145	p1f2q47__1	Num	8	47. Urine dipstick heme (choice=NA)
146	p1f2q47_1	Num	8	47. Urine dipstick heme Test results
147	p1f2q47_2	Num	8	47. Urine dipstick heme Date of Most Recent
148	p1f2q48__1	Num	8	48. Urine microscopic RBCs (choice=NA)
149	p1f2q48_1r	Num	8	48. Urine microscopic RBCs Test results
150	p1f2q48_unit	Num	8	48. Urine microscopic RBCs Unit
151	p1f2q48_1r_2__1	Num	8	48. Urine microscopic RBCs (choice=>100 10^3/mm^3)
152	p1f2q48_2	Num	8	48 . Urine microscopic RBCs Date of Most Recent
153	p1f2q49__1	Num	8	49. Urine microscopic WBCs (choice=NA)
154	p1f2q49_1r	Num	8	49. Urine microscopic WBCs Test results

Num	Variable	Type	Len	Label
155	p1f2q49_unit	Num	8	49. Urine microscopic WBCs Unit
156	p1f2q49_1r_2__1	Num	8	49. Urine microscopic WBCs (choice=>100 10^3/mm^3)
157	p1f2q49_2	Num	8	49. Urine microscopic WBCs Date of Most Recent
158	p1f2q50__1	Num	8	50. Hemoglobin fractionation, baseline(before HU use) (choice=NA)
159	p1f2q50_1	Num	8	50. Hemoglobin fractionation, baseline Hb A
160	p1f2q50_2	Num	8	50. Hemoglobin fractionation, baseline Hb A2
161	p1f2q50_3	Num	8	50. Hemoglobin fractionation, baseline Hb C
162	p1f2q50_4	Num	8	50. Hemoglobin fractionation, baseline Hb D
163	p1f2q50_5	Num	8	50. Hemoglobin fractionation, baseline Hb E
164	p1f2q50_6	Num	8	50. Hemoglobin fractionation, baseline Hb F
165	p1f2q50_7	Num	8	50. Hemoglobin fractionation, baseline Hb O
166	p1f2q50_8	Num	8	50. Hemoglobin fractionation, baseline Hb S
167	p1f2q50_10	Num	8	50. Hemoglobin fractionation, baseline Other
168	p1f2q50_11	Num	8	50. Hemoglobin fractionation, baseline Date of Most Recent
169	p1f2q51__1	Num	8	51. Hemoglobin fractionation, most recent (choice=NA)
170	p1f2q51_1	Num	8	51. Hemoglobin fractionation, most recent Hb A
171	p1f2q51_2	Num	8	51. Hemoglobin fractionation, most recent Hb A2
172	p1f2q51_3	Num	8	51. Hemoglobin fractionation, most recent Hb C
173	p1f2q51_4	Num	8	51. Hemoglobin fractionation, most recent Hb D
174	p1f2q51_5	Num	8	51. Hemoglobin fractionation, most recent Hb E
175	p1f2q51_6	Num	8	51. Hemoglobin fractionation, most recent Hb F
176	p1f2q51_7	Num	8	51. Hemoglobin fractionation, most recent Hb O
177	p1f2q51_8	Num	8	51. Hemoglobin fractionation, most recent Hb S
178	p1f2q51_10	Num	8	51. Hemoglobin fractionation, most recent Other
179	p1f2q51_11	Num	8	51. Hemoglobin fractionation, most recent D51. Hemoglobin fractionation, most recent Date of Most Recent
180	p1f2q52__1	Num	8	52. Hemoglobin fractionation, maximum dose HU (choice=NA)
181	p1f2q52_1	Num	8	52. Hemoglobin fractionation, maximum dose HU Hb A
182	p1f2q52_2	Num	8	52. Hemoglobin fractionation, maximum dose HU Hb A2
183	p1f2q52_3	Num	8	52. Hemoglobin fractionation, maximum dose HU Hb C
184	p1f2q52_4	Num	8	52. Hemoglobin fractionation, maximum dose HU Hb D
185	p1f2q52_5	Num	8	52. Hemoglobin fractionation, maximum dose HU Hb E
186	p1f2q52_6	Num	8	52. Hemoglobin fractionation, maximum dose HU F
187	p1f2q52_7	Num	8	52. Hemoglobin fractionation, maximum dose HU Hb O
188	p1f2q52_8	Num	8	52. Hemoglobin fractionation, maximum dose HU Hb S
189	p1f2q52_10	Num	8	52. Hemoglobin fractionation, maximum dose HU Other
190	p1f2q52_11	Num	8	52. Hemoglobin fractionation, maximum dose HU Date of Most Recent
191	newid	Char	8	Random ID

Data Set Name: *scdregistry_mraform.sas7bdat*

Num	Variable	Type	Len	Label
1	p1flq03a	Num	8	3a. What was the basis for diagnosis?
2	p1flq04	Num	8	4. Approximate age of first diagnosis (physician confirmed)
3	p1flq04a_1	Num	8	4a. Date of most recent visit to pediatric sickle cell provider
4	p1f4q04a_1a__1	Num	8	4a. Date of most recent visit to pediatric sickle cell provider-Date unavailable
5	p1flq04a_2	Num	8	Date of first visit to adult sickle cell provider
6	p1f4q04a_2a__1	Num	8	Date of first visit to adult sickle cell provider-Date unavailable
7	p1f4q04a_2a__2	Num	8	Date of first visit to adult sickle cell provider- has not seen adult provider
8	p1flq04b__1	Num	8	Form complete, medical records not available
9	p1flq05	Num	8	5. Ever tested for alpha-thalassemia?
10	p1flq06__1	Num	8	6. Height -Not in record
11	p1flq07__1	Num	8	7. Weight -Not in record)
12	p1flq08__1	Num	8	8. Temperature -Not in record
13	p1flq08_1	Num	8	8. Temperature (Celsius)
14	p1flq08_2	Num	8	8. Temperature -Date
15	p1flq08_3	Num	8	8. Temperature -Steady state?
16	p1flq09__1	Num	8	9. Heart Rate -Not in record
17	p1flq09_1	Num	8	9. Heart Rate (Beats/Minute)
18	p1flq09_2	Num	8	9. Heart Rate -Date
19	p1flq09_3	Num	8	9. Heart Rate -Steady state?
20	p1flq10__1	Num	8	10. Respiration Rate -Not in record
21	p1flq10_1	Num	8	10. Respiration Rate (Breaths/Minute)
22	p1flq10_2	Num	8	10. Respiration Rate -Date
23	p1flq10_3	Num	8	10. Respiration Rate -Steady state?
24	p1flq11__1	Num	8	11. Oxygen Saturation Level -Not in record
25	p1flq11_1	Num	8	11. Oxygen Saturation Level (SpO2)
26	p1flq11_2	Num	8	11. Oxygen Saturation Level -Date
27	p1flq11_3	Num	8	11. Oxygen Saturation Level -Steady state?
28	p1flq12__1	Num	8	12. Blood Pressure -Not in record
29	p1flq12_1	Num	8	12. Blood Pressure -Systolic
30	p1flq12_2	Num	8	12. Blood Pressure -Diastolic
31	p1flq12_3	Num	8	12. ON ANTI-HYPERTENSIVE MEDS?
32	p1flq12_5	Num	8	12. Blood Pressure -Date
33	p1flq12_6	Num	8	12. Blood Pressure -Steady state?
34	p1flq13	Num	8	13. Has the subject ever used hydroxyurea?
35	p1flq13a	Num	8	13a. Hydroxyurea start date
36	p1flq13b	Num	8	13b. Hydroxyurea Stop/last date
37	p1flq15__1	Num	8	15. Most recent visit to Acute Pain/Infusion Center (not admitted) =Not in record

Num	Variable	Type	Len	Label
38	p1flq15_1	Num	8	15. Acute Pain/Infusion Center-Visit/Admission Date
39	p1flq15_2	Num	8	15. Acute Pain/Infusion Center-was visit for acute pain?
40	p1flq16__1	Num	8	16. Most recent visit to Emergency Department (not admitted) =Not in record
41	p1flq16_1	Num	8	16.ED- Visit/Admission Date
42	p1flq16_2	Num	8	16.ED- Was visit for acute pain?
43	p1flq17__1	Num	8	17. Most recent Hospitalization =Not in record
44	p1flq17_1	Num	8	17.Hospitalization-Visit/Admission Date
45	p1flq17_3	Num	8	17.Hospitalization-Was visit for acute pain?
46	p1flq18__1	Num	8	18.Most recent visit to primary care physician (i. e. family/internal medicine, pediatrician) =Not in record
47	p1flq18_1	Num	8	18. Primary care physician Visit Date
48	p1flq19__1	Num	8	19. Most recent visit to behavioral medicine/psychiatrist =Not in record
49	p1flq19_1	Num	8	19. Behavioral medicine/psychiatrist Visit Date
50	p1flq20__1	Num	8	20. Most recent visit to hematologist =Not in record
51	p1flq20_1	Num	8	20. Hematologist Visit Date
52	p1flq21__1	Num	8	21. Most recent visit to orthopedic surgeon =Not in record
53	p1flq21_1	Num	8	21. Orthopedic surgeon Visit Date
54	p1flq22__1	Num	8	22. Most recent visit to nephrologist =Not in record
55	p1flq22_1	Num	8	22. Nephrologist Visit Date
56	p1flq23__1	Num	8	23. Most recent visit to ophthalmologist =Not in record
57	p1flq23_1	Num	8	23. Ophthalmologist Visit Date
58	p1flq24__1	Num	8	24. Most recent visit to cardiologist =Not in record
59	p1flq24_1	Num	8	24. Cardiologist Visit Date
60	p1flq25__1	Num	8	25. Most recent visit to neurologist =Not in record
61	p1flq25_1	Num	8	25. Neurologist Visit Date
62	p1flq26__1	Num	8	26. Most recent visit to pulmonologist =Not in record
63	p1flq26_1	Num	8	26. Pulmonologist Visit Date
64	p1flq27__1	Num	8	27. Most recent visit to OB/GYN =Not in record
65	p1flq27_1	Num	8	27. OB/GYN Visit Date
66	p1flq28__1	Num	8	28. Transfusion episodic, simple =None
67	p1flq28_3	Num	8	28. Transfusion episodic, simple First time
68	p1flq28_4	Num	8	28. Transfusion episodic, simple Last time
69	p1flq28_5	Num	8	28. Transfusion episodic, simple Frequency
70	p1flq29__1	Num	8	29. Transfusion chronic, simple =None
71	p1flq29_3	Num	8	29. Transfusion chronic, simple First time
72	p1flq29_4	Num	8	29. Transfusion chronic, simple Last time
73	p1flq29_5	Num	8	29. Transfusion chronic, simple Reason stopped
74	p1flq29_6	Num	8	29. Transfusion chronic, simple Frequency
75	p1flq30__1	Num	8	30. Transfusion episodic, exchange =None

Num	Variable	Type	Len	Label
76	p1flq30_2	Num	8	30. Transfusion episodic, exchange First time
77	p1flq30_3	Num	8	30. Transfusion episodic, exchange Last time
78	p1flq30_4	Num	8	30. Transfusion episodic, exchange Frequency
79	p1flq30_5	Num	8	30. Transfusion episodic, exchange Type
80	p1flq31__1	Num	8	31. Transfusion chronic, exchange =None
81	p1flq31_2	Num	8	31. Transfusion chronic, exchange First time
82	p1flq31_3	Num	8	31. Transfusion chronic, exchange Last time
83	p1flq31_4	Num	8	31. Transfusion chronic, exchange Reason stopped
84	p1flq31_5	Num	8	31. Transfusion chronic, exchange Frequency
85	p1flq31_6	Num	8	31. Transfusion chronic, exchange Type
86	p1flq32	Num	8	32. Avascular necrosis
87	p1flq32_1	Num	8	32. Avascular necrosis age
88	p1flq32_2	Num	8	32. Avascular necrosis date
89	p1flq32a	Num	8	32a. Avascular necrosis hip
90	p1flq32a_1	Num	8	32a. Avascular necrosis hip age
91	p1flq32a_2	Num	8	32a. Avascular necrosis hip date
92	p1flq32b	Num	8	32b. Avascular necrosis shoulder
93	p1flq32b_1	Num	8	32b. Avascular necrosis shoulder age
94	p1flq32b_2	Num	8	32b. Avascular necrosis shoulder date
95	p1flq32c	Num	8	32c. Avascular necrosis knee
96	p1flq32c_1	Num	8	32c. Avascular necrosis knee age
97	p1flq32c_2	Num	8	32c. Avascular necrosis knee date
98	p1flq33	Num	8	33. Dactylitis
99	p1flq33_1	Num	8	33. Dactylitis age
100	p1flq33_2	Num	8	33. Dactylitis date
101	p1flq34	Num	8	34. Osteomyelitis
102	p1flq34_1	Num	8	34. Osteomyelitis age
103	p1flq34_2	Num	8	34. Osteomyelitis date
104	p1flq35	Num	8	35. Chronic kidney disease
105	p1flq35_1	Num	8	35. Chronic kidney disease age
106	p1flq35_2	Num	8	35. Chronic kidney disease date
107	p1flq36	Num	8	36. End stage renal disease
108	p1flq36_1	Num	8	36. End stage renal disease age
109	p1flq36_2	Num	8	36. End stage renal disease date
110	p1flq37	Num	8	37. Priapism
111	p1flq37_1	Num	8	37. Priapism age
112	p1flq37_2	Num	8	37. Priapism date
113	p1flq38	Num	8	38. Stroke (check all that apply)
114	p1flq38_1	Num	8	38. Stroke age

Num	Variable	Type	Len	Label
115	p1flq38_2	Num	8	38. Stroke date
116	p1flq38a	Num	8	38a. Stroke Ischemic
117	p1flq38a_1	Num	8	38a. Stroke Ischemic age
118	p1flq38a_2	Num	8	38a. Stroke Ischemic Date
119	p1flq38b	Num	8	38b. Stroke Hemorrhagic
120	p1flq38b_1	Num	8	38b. Stroke Hemorrhagic age
121	p1flq38b_2	Num	8	38b. Stroke Hemorrhagic date
122	p1flq38c	Num	8	38c. Transient ischemic attack (TIA)
123	p1flq38c_1	Num	8	38c. Transient ischemic attack age
124	p1flq38c_2	Num	8	38c. Transient ischemic attack date
125	p1flq38d	Num	8	38d. Stroke Silent
126	p1flq38d_1	Num	8	38d. Stroke age
127	p1flq38d_2	Num	8	38d. Stroke date
128	p1flq39	Num	8	39. Intracranial bleeding
129	p1flq39_1	Num	8	39. Intracranial bleeding age
130	p1flq39_2	Num	8	39. Intracranial bleeding date
131	p1flq40	Num	8	40. Pulmonary arterial hypertension
132	p1flq40_1	Num	8	40. Pulmonary arterial hypertension age
133	p1flq40_2	Num	8	40. Pulmonary arterial hypertension date
134	p1flq40a	Num	8	40a. Mean pulmonary artery pressure > or = to 25 mm Hg
135	p1flq40a_1	Num	8	40a. Mean pulmonary artery pressure > or = to 25 mm Hg age
136	p1flq40a_2	Num	8	40a. Mean pulmonary artery pressure > or = to 25 mm Hg date
137	p1flq40b	Num	8	40b. Tricuspid regurgitation velocity (TRV) > or = to 3.0 m/sec
138	p1flq40b_1	Num	8	40b. TRV > or = to 3.0 m/sec age
139	p1flq40b_2	Num	8	40b. TRV > or = to 3.0 m/sec date
140	p1flq41	Num	8	41. Left ventricular dysfunction
141	p1flq41_1	Num	8	41. Left ventricular dysfunction age
142	p1flq41_2	Num	8	41. Left ventricular dysfunction date
143	p1flq42	Num	8	42. Acute chest syndrome
144	p1flq42_1	Num	8	42. Acute chest syndrome age
145	p1flq42_2	Num	8	42. Acute chest syndrome date
146	p1flq43	Num	8	43. Asthma
147	p1flq43_1	Num	8	43. Asthma age
148	p1flq43_2	Num	8	43. Asthma date
149	p1flq44	Num	8	44. Gallstones/cholelithiasis, cholecystitis
150	p1flq44_1	Num	8	44. Gallstones/cholelithiasis, cholecystitis age
151	p1flq44_2	Num	8	44. Gallstones/cholelithiasis, cholecystitis date
152	p1flq45	Num	8	45. Splenomegaly (check all that apply)
153	p1flq45_1	Num	8	45. Splenomegaly age

Num	Variable	Type	Len	Label
154	p1flq45_2	Num	8	45. Splenomegaly date
155	p1flq45a	Num	8	45a. Splenic sequestration
156	p1flq45a_1	Num	8	45a. Splenic sequestration age
157	p1flq45a_2	Num	8	45a. Splenic sequestration date
158	p1flq45b	Num	8	45b. Splenic infarcts
159	p1flq45b_1	Num	8	45b. Splenic infarcts age
160	p1flq45b_2	Num	8	45b. Splenic infarcts date
161	p1flq45c	Num	8	45c. Hypersplenism
162	p1flq45c_1	Num	8	45c. Hypersplenism age
163	p1flq45c_2	Num	8	45c. Hypersplenism date
164	p1flq45d	Num	8	45d. Splenectomy
165	p1flq45d_1	Num	8	45d. Splenectomy age
166	p1flq45d_2	Num	8	45d. Splenectomy date
167	p1flq46	Num	8	46. Deep vein thrombosis (DVT)
168	p1flq46_1	Num	8	46. Deep vein thrombosis age
169	p1flq46_2	Num	8	46. Deep vein thrombosis date
170	p1flq46a	Num	8	46a. Pulmonary embolism
171	p1flq46a_1	Num	8	46a. Pulmonary embolism age
172	p1flq46a_2	Num	8	46a. Pulmonary embolism date
173	p1flq46b	Num	8	46b. Venous thromboembolism (VTE)
174	p1flq46b_1	Num	8	46b. Venous thromboembolism age
175	p1flq46b_2	Num	8	46b. Venous thromboembolism date
176	p1flq47	Num	8	47. Lupus
177	p1flq47_1	Num	8	47. Lupus age
178	p1flq47_2	Num	8	47. Lupus date
179	p1flq48	Num	8	48. Rheumatoid arthritis
180	p1flq48_1	Num	8	48. Rheumatoid arthritis age
181	p1flq48_2	Num	8	48. Rheumatoid arthritis date
182	p1flq49	Num	8	49. Gout
183	p1flq49_1	Num	8	49. Gout age
184	p1flq49_2	Num	8	49. Gout date
185	p1flq50	Num	8	50. Sarcoidosis
186	p1flq50_1	Num	8	50. Sarcoidosis age
187	p1flq50_2	Num	8	50. Sarcoidosis date
188	p1flq51	Num	8	51. Other autoimmune or inflammatory
189	p1flq51_2	Num	8	51. Other autoimmune or inflammatory age
190	p1flq51_3	Num	8	51. Other autoimmune or inflammatory date
191	p1flq52	Num	8	52. Multi-organ failure (check all that apply)
192	p1flq52_1	Num	8	52. Multi-organ failure age

Num	Variable	Type	Len	Label
193	p1flq52_2	Num	8	52. Multi-organ failure date
194	p1flq52a	Num	8	52a. Multi-organ failure: ICU
195	p1flq52a_1	Num	8	52a. Multi-organ failure:ICU age
196	p1flq52a_2	Num	8	52a. Multi-organ failure:ICU date
197	p1flq52b	Num	8	52b. Multi-organ failure: Intubation
198	p1flq52b_1	Num	8	52b. Multi-organ failure: Intubation age
199	p1flq52b_2	Num	8	52b. Multi-organ failure: Intubation date
200	p1flq52c	Num	8	52c. Multi-organ failure: Simple transfusion
201	p1flq52c_1	Num	8	52c. Multi-organ failure: Simple transfusion age
202	p1flq52c_2	Num	8	52c. Multi-organ failure: Simple transfusion date
203	p1flq52d	Num	8	52d. Multi-organ failure: Exchange transfusion
204	p1flq52d_1	Num	8	52d. Multi-organ failure: Exchange transfusion age
205	p1flq52d_2	Num	8	52d. Multi-organ failure: Exchange transfusion date
206	p1flq52e	Num	8	52e. Multi-organ failure: Hemodialysis
207	p1flq52e_1	Num	8	52e. Multi-organ failure: Hemodialysis age
208	p1flq52e_2	Num	8	52e. Multi-organ failure: Hemodialysis date
209	p1flq52f	Num	8	52f. Multi-organ failure: Peritoneal dialysis
210	p1flq52f_1	Num	8	52f. Multi-organ failure: Peritoneal dialysis age
211	p1flq52f_2	Num	8	52f. Multi-organ failure: Peritoneal dialysis date
212	p1flq53	Num	8	53. Pneumococcal sepsis (Pulmonary)
213	p1flq53_1	Num	8	53. Pneumococcal sepsis age
214	p1flq53_2	Num	8	53. Pneumococcal sepsis date
215	p1flq54	Num	8	54. Skin ulcers (Integumentary)
216	p1flq54_1	Num	8	54. Skin ulcers age
217	p1flq54_2	Num	8	54. Skin ulcers date
218	p1flq55	Num	8	55. Retinopathy (Ocular)
219	p1flq55_1	Num	8	55. Retinopathy age
220	p1flq55_2	Num	8	55. Retinopathy date
221	p1flq56	Num	8	56. Diabetes mellitus (other systemic)
222	p1flq56_1	Num	8	56. Diabetes mellitus age
223	p1flq56_2	Num	8	56. Diabetes mellitus date
224	p1flq57	Num	8	57. Iron overload (Other)
225	p1flq57_1	Num	8	57. Iron overload age
226	p1flq57_2	Num	8	57. Iron overload date
227	p1flq58	Num	8	58. Chronic refractory pain (Other)
228	p1flq58_1	Num	8	58. Chronic refractory pain age
229	p1flq58_2	Num	8	58. Chronic refractory pain date
230	p1flq59	Num	8	59. Anxiety (Mental health)
231	p1flq59_1	Num	8	59. Anxiety age

Num	Variable	Type	Len	Label
232	p1flq59_2	Num	8	59. Anxiety date
233	p1flq60	Num	8	60. Depression (Mental health)
234	p1flq60_1	Num	8	60. Depression age
235	p1flq60_2	Num	8	60. Depression date
236	p1flq61	Num	8	61. Other psychiatric disorder (Mental health)
237	p1flq61_2	Num	8	61. Other psychiatric disorder age
238	p1flq61_3	Num	8	61. Other psychiatric disorder date
239	p1flq64	Num	8	64. First visit in medical record
240	p1flq63_copy___98	Num	8	63. What kind of health insurance or health care coverage does the subject have at the time of enrollment?=None
241	p1flq63_copy___1	Num	8	63. What kind of health insurance or health care coverage does the subject have at the time of enrollment? Private health insurance
242	p1flq63_copy___2	Num	8	63. What kind of health insurance or health care coverage does the subject have at the time of enrollment? Medicare
243	p1flq63_copy___3	Num	8	63. What kind of health insurance or health care coverage does the subject have at the time of enrollment? Medicaid, Medical Assistance (MA), the Childrens Health Insurance Program (CHIP), or any kind of state or government-sponsored assistance.
244	p1flq63_copy___4	Num	8	63. What kind of health insurance or health care coverage does the subject have at the time of enrollment? TRICARE or other military health care, including VA health care
245	newid	Char	8	Random ID
246	bmi	Num	8	BMI
247	bmi_dt	Num	8	BMI date
248	p1flq03R	Num	8	3.Confirmed enrollment diagnosis (recoded)
249	p1flq15_3R	Char	3	15. Acute Pain/Infusion Center- # of total visits in past year for acute pain/crisis (recoded)
250	p1flq16_3R	Char	3	16. ED- # of total visits in past year for acute pain/crisis (recoded)
251	p1flq17_2R	Char	3	17.Hospitalization-Length of stay (in days) (recoded)
252	p1flq17_4R	Char	3	17.Hospitalization-# of total visits in past year for acute pain/crisis (recoded)
253	p1flq02R	Num	8	2. Location where person enrolled (recoded)
254	p1flq64aR	Char	9	64a. Year of first visit in medical record (recoded)
255	p1flq28_1	Num	8	28. Transfusion episodic, simple # ever had
256	p1flq28_2	Num	8	28. Transfusion episodic, simple # total units
257	p1flq29_1	Num	8	29. Transfusion chronic, simple # ever had
258	p1flq29_2	Num	8	29. Transfusion chronic, simple # total units
259	p1flq30_1	Num	8	30. Transfusion episodic, exchange # ever had
260	p1flq31_1	Num	8	31. Transfusion chronic, exchange # ever had
261	medscountR	Char	5	Number of medications currently taking (recoded)

Data Set Name: *scdregistry_ptsurvey.sas7bdat*

Num	Variable	Type	Len	Label
1	p1f5q1	Num	8	1. What is today 's date?
2	p1f5q3	Num	8	3. How old are you today?
3	p1f5q6	Num	8	6. Do you take pain medicine every day for your sickle cell disease?
4	p1f5q7	Num	8	7. In the past 12 months, how many sickle cell pain attacks (crises) did you have?
5	p1f5q8	Num	8	8. When was your last pain attack (crisis)?
6	p1f5q9	Num	8	9. How severe was your pain during your last pain attack (crisis)? Circle a number from 0 to 10 below, where 0 is no pain and 10 is the worst pain imaginable.
7	p1f5q10	Num	8	10. How much did your last pain attack (crisis) interfere with your life?
8	p1f5q11	Num	8	11. About how long did your most recent pain attack (crisis) last?
9	p1f5q12a	Num	8	12a. How often did you have very severe pain?
10	p1f5q12b	Num	8	12b. How often did you have pain so bad that it was hard to finish what you were doing?
11	p1f5q13a	Num	8	13a. How often did you have very severe pain?
12	p1f5q13b	Num	8	13b. How often did you have pain so bad that it was hard to finish what you were doing?
13	p1f5q14a	Num	8	14a. Did your pain feel like pins and needles?
14	p1f5q14b	Num	8	14b. Did your pain feel sore?
15	p1f5q15	Num	8	15. Did a doctor ever suggest you take hydroxyurea?
16	p1f5q17	Num	8	17. Have you ever taken hydroxyurea?
17	p1f5q18	Num	8	18. Have you experienced any side effects related to hydroxyurea?
18	p1f5q20	Num	8	20. Are you currently on hydroxyurea?
19	p1f5q21	Num	8	21. How many days did you take hydroxyurea in the PAST WEEK?
20	p1f5q23	Num	8	23. Do you get regular blood transfusions for your sickle cell disease?
21	p1f5q24	Num	8	24. Estimate the number of units (pints) of blood that you have ever received.
22	p1f5q25	Num	8	25. Are you on iron chelation treatment at this time?
23	p1f5q26	Num	8	26. Have you ever been told that it is difficult to find blood for you (i. e. , you have antibodies or react to other people"s blood red blood cells)?
24	p1f5q27	Num	8	27. Have you ever been referred for a bone marrow transplant?
25	p1f5q28a	Num	8	28a. Has a doctor or nurse ever told you that you have or had any of the following conditions? Lung problems such as pneumonia or acute chest syndrome
26	p1f5q28b	Num	8	28b. Has a doctor or nurse ever told you that you have or had any of the following conditions? Kidney damage
27	p1f5q28c	Num	8	28c. Has a doctor or nurse ever told you that you have or had any of the following conditions? Has a doctor or nurse ever told you that you have or had any of the following conditions? Eye damage called retinopathy
28	p1f5q28d	Num	8	28d. Has a doctor or nurse ever told you that you have or had any of the following conditions? Damage to your hip or shoulder due to sickle cell disease
29	p1f5q28e	Num	8	28e. Has a doctor or nurse ever told you that you have or had any of the following conditions? High blood pressure in your lungs (also called pulmonary hypertension)
30	p1f5q28f	Num	8	28f. Has a doctor or nurse ever told you that you have or had any of the following conditions? Heart failure
31	p1f5q28g	Num	8	28g. Has a doctor or nurse ever told you that you have or had any of the following conditions? Blood clots in your legs or arms or that went to your lung

Num	Variable	Type	Len	Label
32	p1f5q28h	Num	8	28h. Has a doctor or nurse ever told you that you have or had any of the following conditions? A stroke
33	p1f5q28i	Num	8	28i. Has a doctor or nurse ever told you that you have or had any of the following conditions? Asthma
34	p1f5q28j	Num	8	28j. Has a doctor or nurse ever told you that you have or had any of the following conditions? Diabetes
35	p1f5q29	Num	8	29. Have you ever had open sores on your legs or feet (leg ulcers)?
36	p1f5q30	Num	8	30. Has your spleen either been removed or seriously damaged due to sickle cell disease?
37	p1f5q32	Num	8	32. 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?
38	p1f5q34a	Num	8	34a. How often did you stay up most of the night because you could not fall asleep?
39	p1f5q34b	Num	8	34b. How often did you have a lot of trouble falling asleep?
40	p1f5q35a	Num	8	35a. I had to read something several times to understand it.
41	p1f5q35b	Num	8	35b. My thinking was slow.
42	p1f5q35c	Num	8	35c. I had to work really hard to pay attention or I would make a mistake.
43	p1f5q35d	Num	8	35d. I had trouble concentrating.
44	p1f5q36a	Num	8	36a. Reading and following complex instructions (e. g. , directions for a new medication)?
45	p1f5q36b	Num	8	36b. Planning for and keeping appointments that are not part of your weekly routine (e. g. , a therapy or doctor appointment, a social gathering with friends or family)?
46	p1f5q36c	Num	8	36c. Managing your time to do most of your daily activities?
47	p1f5q36d	Num	8	36d. Learning new tasks or instructions?
48	p1f5q37a	Num	8	37a. I felt worthless.
49	p1f5q37b	Num	8	37b. I felt helpless.
50	p1f5q37c	Num	8	37c. I felt depressed.
51	p1f5q37d	Num	8	37d. I felt hopeless.
52	p1f5q37e	Num	8	37e. How often did you feel completely hopeless because of your health?
53	p1f5q37f	Num	8	37f. How often were you very worried about needing to go to the hospital?
54	p1f5q37g	Num	8	37g. I felt tired.
55	p1f5q38	Num	8	38. Have you ever been treated for depression?
56	p1f5q39a	Num	8	39a. How much did you rely on others to take care of you because of your health?
57	p1f5q39b	Num	8	39b. How much did your health make it hard for you to do things with your friends?
58	p1f5q40	Num	8	40. Are you male or female?
59	p1f5q41	Num	8	41. Do you consider yourself Hispanic/Latino or not Hispanic/Latino?
60	p1f5q42__1	Num	8	42. Which of the following five racial designations best describes you? (More than one choice is acceptable) American Indian or Alaska Native
61	p1f5q42__2	Num	8	Which of the following five racial designations best describes you? (More than one choice is acceptable) Asian, Native Hawaiian or Pacific Islander
62	p1f5q42__3	Num	8	42. Which of the following five racial designations best describes you? (More than one choice is acceptable) Black or African American
63	p1f5q42__5	Num	8	42. Which of the following five racial designations best describes you? (More than one choice is acceptable) White
64	p1f5q46	Num	8	46. What is your approximate yearly household income? Include income from all sources.

Num	Variable	Type	Len	Label
65	p1f5q47	Num	8	47. What is the highest grade or level of school you have completed or the highest degree you have received?
66	p1f5q48	Num	8	48. We would like to know about what you do -- are you working, looking for work, retired, keeping house, or what?
67	p1f5q5r_copy	Num	8	5. What type of healthcare professional has been providing the majority of care for your sickle cell disease in the past 2 years?
68	p1f5q16_copy__1	Num	8	16.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
69	p1f5q16_copy__2	Num	8	16.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
70	p1f5q16_copy__3	Num	8	16.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
71	p1f5q16_copy__4	Num	8	16.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
72	p1f5q16_copy__5	Num	8	16.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
73	p1f5q16_copy__6	Num	8	16.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
74	p1f5q16_copy__7	Num	8	16.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
75	p1f5q16_copy__8	Num	8	16.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
76	p1f5q16_copy__9	Num	8	16.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
77	p1f5q16_copy__10	Num	8	16.What makes it difficult for you to take hydroxyurea or is there a reason why you do not take hydroxyurea? Other difficulty, specify
78	p1f5q16_copy__11	Num	8	16.What makes it difficult for you to take hydroxyurea or is there a reason why you do not take hydroxyurea? Allergic
79	p1f5q16_copy__12	Num	8	16.What makes it difficult for you to take hydroxyurea or is there a reason why you do not take hydroxyurea? Does not work/help
80	p1f5q16_copy__13	Num	8	16.What makes it difficult for you to take hydroxyurea or is there a reason why you do not take hydroxyurea? Pregnant/trying to conceive/nursing
81	p1f5q16_copy__14	Num	8	16.What makes it difficult for you to take hydroxyurea or is there a reason why you do not take hydroxyurea? Taste/difficulty swallowing/dont like taking pills
82	p1f5q16_copy__15	Num	8	16.What makes it difficult for you to take hydroxyurea or is there a reason why you do not take hydroxyurea? Personal preference
83	p1f5q16_copy__16	Num	8	16.What makes it difficult for you to take hydroxyurea or is there a reason why you do not take hydroxyurea? Doctor directed me to stop or not start taking hydroxyurea
84	p1f5q16_copy__17	Num	8	16.What makes it difficult for you to take hydroxyurea or is there a reason why you do not take hydroxyurea? Moved to alternative treatment
85	p1f5q19_copy__1	Num	8	19.What side effects have you experienced while you were taking hydroxyurea? Hair loss/thinning
86	p1f5q19_copy__2	Num	8	19.What side effects have you experienced while you were taking hydroxyurea? Nail blackening or discoloration
87	p1f5q19_copy__3	Num	8	19.What side effects have you experienced while you were taking hydroxyurea? Lowered blood counts (e.g., platelets, white count, hemoglobin)

Num	Variable	Type	Len	Label
88	p1f5q19_copy__4	Num	8	19.What side effects have you experienced while you were taking hydroxyurea? Low sperm count or other fertility problems
89	p1f5q19_copy__5	Num	8	19.What side effects have you experienced while you were taking hydroxyurea? Nausea/vomiting
90	p1f5q19_copy__6	Num	8	19.What side effects have you experienced while you were taking hydroxyurea? Skin ulcers
91	p1f5q19_copy__7	Num	8	19.What side effects have you experienced while you were taking hydroxyurea? Weight gain
92	p1f5q19_copy__8	Num	8	19.What side effects have you experienced while you were taking hydroxyurea? Headaches or dizziness
93	p1f5q19_copy__9	Num	8	19.What side effects have you experienced while you were taking hydroxyurea? Fatigue/drowsiness
94	p1f5q19_copy__10	Num	8	19.What side effects have you experienced while you were taking hydroxyurea? Acne/skin problems
95	p1f5q19_copy__11	Num	8	19.What side effects have you experienced while you were taking hydroxyurea? GI / stomach problems
96	p1f5q19_copy__12	Num	8	19.What side effects have you experienced while you were taking hydroxyurea? Appetite changes
97	p1f5q19_copy__13	Num	8	19.What side effects have you experienced while you were taking hydroxyurea? Pain/aches
98	p1f5q19_copy__14	Num	8	19.What side effects have you experienced while you were taking hydroxyurea? Swelling
99	p1f5q19_copy__15	Num	8	19.What side effects have you experienced while you were taking hydroxyurea? Weight loss
100	p1f5q19_copy__16	Num	8	19.What side effects have you experienced while you were taking hydroxyurea? Eye/vision problems
101	p1f5q19_copy__17	Num	8	19.What side effects have you experienced while you were taking hydroxyurea? Mouth/oral problems
102	p1f5q19_copy__18	Num	8	19.What side effects have you experienced while you were taking hydroxyurea? Depression/mood swings
103	p1f5q19_copy__19	Num	8	19.What side effects have you experienced while you were taking hydroxyurea? Liver and kidney problems
104	p1f5q19_copy__99	Num	8	19.What side effects have you experienced while you were taking hydroxyurea? Other
105	p1f5q22_copy	Num	8	22.What is the reason you discontinued or stopped taking hydroxyurea?
106	p1f5q33_copy__1	Num	8	33.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
107	p1f5q33_copy__2	Num	8	33.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 wouldnt accept your health insurance
108	p1f5q33_copy__3	Num	8	33.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 wouldnt pay for the treatment
109	p1f5q33_copy__4	Num	8	33.Did you not get the medical care you needed or have delays getting medical care you needed for any of the following reasons? You couldnt get an appointment soon enough
110	p1f5q33_copy__5	Num	8	33.Did you not get the medical care you needed or have delays getting medical care you needed for any of the following reasons? You couldnt get there when the doctors office or clinic was open
111	p1f5q33_copy__6	Num	8	33.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 doctors office or clinic from your house or work
112	p1f5q33_copy__7	Num	8	33.Did you not get the medical care you needed or have delays getting medical care you needed for any of the following reasons? You couldnt get through on the telephone

Num	Variable	Type	Len	Label
113	p1f5q33_copy__8	Num	8	33.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
114	p1f5q33_copy__9	Num	8	33.Did you not get the medical care you needed or have delays getting medical care you needed for any of the following reasons? You didnt think the problem was serious enough
115	p1f5q33_copy__10	Num	8	33.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
116	p1f5q33_copy__11	Num	8	33.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 doctors office or clinic dont speak the same language I do
117	p1f5q33_copy__12	Num	8	33.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, please specify
118	p1f5q33_copy__13	Num	8	33.Did you not get the medical care you needed or have delays getting medical care you needed for any of the following reasons? Issues with ER/ED
119	p1f5q33_copy__14	Num	8	33.Did you not get the medical care you needed or have delays getting medical care you needed for any of the following reasons? Doctor not available (eg. out of town)
120	p1f5q33_copy__15	Num	8	33.Did you not get the medical care you needed or have delays getting medical care you needed for any of the following reasons? Incarcerated
121	p1f5q33_copy__16	Num	8	33.Did you not get the medical care you needed or have delays getting medical care you needed for any of the following reasons? Lack of health insurance
122	p1f5q33_copy__17	Num	8	33.Did you not get the medical care you needed or have delays getting medical care you needed for any of the following reasons? Lack of transportation
123	newid	Char	8	Random ID
124	p1f5q4R	Char	5	4. How old were you when you were diagnosed with sickle cell disease? (recoded)
125	p1f5q45aR	Char	5	45.How many children and adults, including yourself, live in your household at least 4 nights a week? # of children(recoded)
126	p1f5q45bR	Char	5	45.How many children and adults, including yourself, live in your household at least 4 nights a week? # of adults(recoded)
127	medscountR	Char	5	Number of medications currently taking (recoded)
128	p1f5q43R	Num	8	43. In at language do you feel most comfortable speaking with your doctor or nurse? (recoded)
129	p1f5q44R	Num	8	44. What is your current marital status? (recoded)

Data Set Name: *scdregistry_pulmonaryht.sas7bdat*

Num	Variable	Type	Len	Label
1	newid	Char	8	Random ID
2	p1f9q00	Num	8	Date Form Completed
3	p1f9q00b___1	Num	8	Most recent ECHO/ ECHO not available
4	p1f9q00b2	Num	8	Date of most recent ECHO
5	pf9q01	Num	8	1. Mitral regurgitation- Qualitative data
6	p1f9q02	Num	8	2. Tricuspid regurgitation-Qualitative data
7	p1f9q03_a___1	Num	8	3. TR jet velocity NA
8	p1f9q03	Num	8	3. TR jet velocity: Quantitative data
9	p1f9q03_b	Num	8	3. TR jet velocity: Unit
10	p1f9q04_a___1	Num	8	4. Tricuspid Annular Plane Systolic Excursion: NA
11	p1f9q04	Num	8	4. Tricuspid Annular Plane Systolic Excursion: Quantitative data
12	p1f9q05_a___1	Num	8	5. Ejection fraction, left ventricle: NA
13	p1f9q05	Num	8	5. Ejection fraction, left ventricle: Quantitative data
14	p1f9q06___1	Num	8	6. Left Atrial Volume: NA
15	p1f9q06_a_na___1	Num	8	6. Left Atrial Volume: Qualitative data NA
16	p1f9q06_a	Num	8	6. Left Atrial Volume: Qualitative data
17	p1f9q06_b_na___1	Num	8	6. Left Atrial Volume: Quantitative data NA
18	p1f9q06_b	Num	8	6. Left Atrial Volume:LAESVI
19	p1f9q07___1	Num	8	7. Right Atrial Volume: NA
20	p1f9q07_a	Num	8	7. Right Atrial Volume: Qualitative data
21	p1f9q07_b	Num	8	7. Right Atrial Volume: RAESVI
22	p1f9q08___1	Num	8	8. Left ventricular volume: NA
23	p1f9q08_a	Num	8	8. Left ventricular volume: Qualitative data
24	p1f9q08_b1	Num	8	8. Left ventricular volume: LVIDs
25	p1f9q08_b1b	Num	8	8. Left ventricular volume: LVID Unit
26	p1f9q08_b2	Num	8	8. Left ventricular volume: LVESVI
27	p1f9q08_b3	Num	8	8. Left ventricular volume: LVIDd
28	p1f9q08_b3b	Num	8	8. Left ventricular volume: LVIDd Unit
29	p1f9q08_b4	Num	8	8. Left ventricular volume: LVPwD
30	p1f9q08_b4b	Num	8	8. Left ventricular volume LVPwD: Unit
31	p1f9q09___1	Num	8	9. Right ventricular volume: NA
32	p1f9q09_a	Num	8	9. Right ventricular volume: Qualitative data
33	p1f9q09_b1	Num	8	9. Right ventricular volume: RVIDs
34	p1f9q09_b2	Num	8	9. Right ventricular volume: RVIDd
35	p1f9q09_b3	Num	8	9. Right ventricular volume: Mention of interventricular septal flattening
36	p1f9q10_a___1	Num	8	10. RV hypertrophy: NA
37	p1f9q10	Num	8	10. RV hypertrophy: Qualitative data

Num	Variable	Type	Len	Label
38	p1f9q11___1	Num	8	11. Most recent EKG: EKG not available
39	p1f9q11_2	Num	8	11. Date of Most recent EKG
40	p1f9q11_a	Num	8	11. Arrhythmia diagnosed?
41	p1f9q12_a___1	Num	8	12. Ventricular rate: NA
42	p1f9q12_b	Num	8	12. Ventricular rate
43	p1f9q13_a___1	Num	8	13. PR Interval: NA
44	p1f9q13_b	Num	8	13. PR Interval
45	p1f9q14_a___1	Num	8	14. QRS duration: NA
46	p1f9q14_b	Num	8	14. QRS duration
47	p1f9q15_a___1	Num	8	15. QT/QTc: NA
48	p1f9q15_b	Char	11	15. QT/QTc
49	p1f9q16_a___1	Num	8	16. P-R-T axes: NA
50	p1f9q16_b	Char	14	16. P-R-T axes
51	p1f9q17_1___1	Num	8	17. Most recent right heart catheterization: Report not available
52	p1f9q17_2	Num	8	17. Date of most recent right heart catheterization
53	p1f9q17_a___1	Num	8	17. RA pressure (mean): NA
54	p1f9q17_b	Num	8	17.RA pressure (mean)
55	p1f9q18_a___1	Num	8	18. RV pressure (mean): NA
56	p1f9q18_b	Num	8	18. RV pressure (mean)
57	p1f9q19_a___1	Num	8	19. PA pressure (mean): NA
58	p1f9q19_b	Num	8	19. PA pressure (mean)
59	p1f9q20_a___1	Num	8	20. Pulmonary artery saturation: NA
60	p1f9q20_b	Num	8	20. Pulmonary artery saturation
61	p1f9q21_a___1	Num	8	21. Pulmonary vascular resistance: NA
62	p1f9q21_b	Num	8	21. Pulmonary vascular resistance
63	p1f9q22_a___1	Num	8	22. Pulmonary capillary wedge pressure (PCWP or PAWP): NA
64	p1f9q22_b	Num	8	22. Pulmonary capillary wedge pressure (PCWP or PAWP)
65	p1f9q23_a___1	Num	8	23. Cardiac output and index: NA
66	p1f9q23_b	Num	8	23. Cardiac output and index

Data Set Name: *scdregistry_renalform.sas7bdat*

Num	Variable	Type	Len	Label
1	newid	Char	8	Random ID
2	p1f8q00	Num	8	DATE FORM COMPLETED
3	p1f8q01_a2	Num	8	1a. Albuminuria-When did it start (date)?
4	p1f8q01_a	Num	8	1a. Albuminuria-When did it start (code)?
5	p1f8q01_b2	Num	8	1b. Albuminuria-Date of most recent measurement (date)
6	p1f8q01_b	Num	8	1b. Albuminuria-Date of most recent measurement (code)
7	p1f8q01_c	Num	8	1c. Albuminuria-Type of measurement (check one)
8	p1f8q01_d	Num	8	1d. Albuminuria-Spot urine sample (milligram albumin per liter of urine)
9	p1f8q01_e	Num	8	1e. Albuminuria-Spot urine albumin/ creatinine ratio
10	p1f8q01_e2	Num	8	1e Albuminuria-Unit for Spot urine
11	p1f8q02_a2	Num	8	2a. Proteinuria-When did it start (date)?
12	p1f8q02_a	Num	8	2a. Proteinuria-When did it start (code)
13	p1f8q02_b2	Num	8	2b. Date of most recent measurement (date)
14	p1f8q02_b	Num	8	2b. Date of most recent measurement (code)
15	p1f8q02_c	Num	8	2c. Type of measurement (check one)
16	p1f8q02_d	Num	8	2d. Spot urine sample (milligram protein per liter of urine)
17	p1f8q02_e	Num	8	2e. Spot urine protein/creatinine ratio
18	p1f8q02_e2	Num	8	2e. Unit for Spot urine
19	p1f8q03a_2	Num	8	3a. eGFR <60-When did it start (date)?
20	p1f8q03a	Num	8	3a. eGFR <60-When did it start (code)?
21	p1f8q03b_2	Num	8	3b. eGFR <60-Date of most recent measurement(date)?
22	p1f8q03b	Num	8	3b. eGFR <60-Date of most recent measurement(code)?
23	p1f8q04a	Num	8	4a. History of acute kidney injury (AKI*)
24	p1f8q04b	Num	8	4b. History of >1 episode of AKI*
25	p1f8q04c	Num	8	4c. Hemodialysis
26	p1f8q04d	Num	8	4d. Peritoneal dialysis
27	p1f8q04e	Num	8	4e. Kidney disease/ESRD
28	p1f8q04e_b	Num	8	4e. Date of Kidney disease/ERSD (date)
29	p1f8q04e_a	Num	8	4e. Date of Kidney disease/ERSD (code)
30	p1f8q04f	Num	8	4f. Kidney transplant
31	p1f8q04f_b	Num	8	4f. Kidney transplant date
32	p1f8q04f_a__1	Num	8	4f. Kidney transplant: Unknown/NA
33	p1f8q04f_c	Num	8	4f. Kidney transplant: Rejection?