

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 | p2f1_opt_out__1 | Num | 8 | The patient has opted out of taking this survey |
| 2 | p2f1q00 | Num | 8 | What is today's date? |
| 3 | p2f1q01 | Num | 8 | 1. Do you take pain medicine every day for your sickle cell disease? |
| 4 | p2f1q02__1 | Num | 8 | 2. What pain medicines do you currently take for your sickle cell disease? Dont take pain medicines. |
| 5 | p2f1q03 | Num | 8 | 3. In the past 12 months, how many sickle cell pain attacks (crises) did you have? |
| 6 | p2f1q04 | Num | 8 | 4. When was your last pain attack (crisis)? |
| 7 | p2f1q05 | 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 | p2f1q06 | Num | 8 | 6. How much did your last pain attack (crisis) interfere with your life? |
| 9 | p2f1q07 | Num | 8 | 7. About how long did your most recent pain attack (crisis) last? |
| 10 | p2f1q08a | Num | 8 | 8a. In the past 7 days, how often did you have very severe pain? |
| 11 | p2f1q08b | 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 | p2f1q09a | Num | 8 | 9a. In the past 6 months, how often did you have very severe pain? |
| 13 | p2f1q09b | 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 | p2f1q10a | Num | 8 | 10a. In the past 7 days, did your pain feel like pins and needles? |
| 15 | p2f1q10b | Num | 8 | 10b. In the past 7 days, did your pain feel sore? |
| 16 | p2f1q11 | Num | 8 | 11. Would you say that your pain management plan is.... |
| 17 | p2f1q12 | Num | 8 | 12. Do you get regular blood transfusions for your sickle cell disease? |
| 18 | p2f1q13 | Num | 8 | 13. In the past 12 months, how many units (pints) of blood have you received? |
| 19 | p2f1q14 | Num | 8 | 14. Are you currently on iron chelation treatment (e.g., Desferal, Exjade, Jadenu, deferasirox, Ferriprox, deferiprone, phlebotomy)? |
| 20 | p2f1q15 | Num | 8 | 15. In the past 12 months, has your spleen been removed? |
| 21 | p2f1q16a | Num | 8 | 16a. In the past 12 months, have you been newly diagnosed with lung problems such as pneumonia or acute chest syndrome |
| 22 | p2f1q16b | Num | 8 | 16b. In the past 12 months, have you been newly diagnosed with kidney damage |
| 23 | p2f1q16c | Num | 8 | 16c. In the past 12 months, have you been newly diagnosed with eye damage called retinopathy |
| 24 | p2f1q16d | 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 | p2f1q16e | 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 | p2f1q16f | Num | 8 | 16f. In the past 12 months, have you been newly diagnosed with heart failure |
| 27 | p2f1q16g | 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 | p2f1q16h | Num | 8 | 16h. In the past 12 months, have you been newly diagnosed with a stroke |
| 29 | p2f1q16i | Num | 8 | 16i. In the past 12 months, have you been newly diagnosed with asthma |
| 30 | p2f1q16j | Num | 8 | 16j. In the past 12 months, have you been newly diagnosed with diabetes |

| Num | Variable | Type | Len | Label |
|-----|-------------|------|-----|---|
| 31 | p2f1q16k | Num | 8 | 16k. In the past 12 months, have you been newly diagnosed with liver problems such as hepatitis, iron overload, or cirrhosis |
| 32 | p2f1q16l | Num | 8 | 16l. In the past 12 months, have you been newly diagnosed with skin ulcers |
| 33 | p2f1q17 | Num | 8 | 19. In the past 12 months, have you taken hydroxyurea? |
| 34 | p2f1q18 | Num | 8 | 20. Are you currently taking hydroxyurea? |
| 35 | p2f1q19 | Num | 8 | 21. In the past 12 months, what is the reason you discontinued or stopped taking hydroxyurea? |
| 36 | p2f1q20 | Num | 8 | 22. How many days did you take hydroxyurea in the PAST WEEK? |
| 37 | p2f1q21__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 | p2f1q21__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 | p2f1q21__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 | p2f1q21__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 | p2f1q21__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 | p2f1q21__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 | p2f1q21__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 | p2f1q21__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 | p2f1q21__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 | p2f1q21__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 | p2f1q22__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 | p2f1q22__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 | p2f1q22__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 | p2f1q22__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 | p2f1q22__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 | p2f1q22__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 | p2f1q22__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 | p2f1q22__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 | p2f1q22__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 | p2f1q22__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 | p2f1q23 | Num | 8 | 25. In the past 12 months, have you taken the drug called Endari (l-glutamine)? |
| 58 | p2f1q24 | Num | 8 | 26. Are you currently taking Endari? |
| 59 | p2f1q25 | 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 | p2f1q26 | Num | 8 | 28. How many days did you take Endari in the PAST WEEK? |
| 61 | p2f1q27__1 | Num | 8 | 29. In the last 12 months, what side effects have you experienced while you were taking Endari? No side effects |
| 62 | p2f1q27__2 | Num | 8 | 29. In the last 12 months, what side effects have you experienced while you were taking Endari? Nausea/vomiting |
| 63 | p2f1q27__3 | Num | 8 | 29. In the last 12 months, what side effects have you experienced while you were taking Endari? Stomach pain |
| 64 | p2f1q27__4 | Num | 8 | 29. In the last 12 months, what side effects have you experienced while you were taking Endari? Cough |
| 65 | p2f1q27__5 | Num | 8 | 29. In the last 12 months, what side effects have you experienced while you were taking Endari? Headaches or dizziness |
| 66 | p2f1q27__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 | p2f1q29 | Num | 8 | 41. Are you taking any medications for high blood pressure (hypertension) or for your heart? |
| 68 | p2f1q30 | Num | 8 | 42. Are you taking any other type of medication that we did not already ask about? |
| 69 | p2f1q31 | Num | 8 | 43. Are you currently participating in a study where you are taking a medicine for sickle cell? |
| 70 | p2f1q32a | 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 | p2f1q32b | Num | 8 | 32b. Think about your sleep in the past 7 days, how often did you have a lot of trouble falling asleep? |
| 72 | p2f1q33a_v3 | Num | 8 | 33av3. I have someone who will listen to me when I need to talk |
| 73 | p2f1q33b_v3 | Num | 8 | 33bv3. I have someone to confide in or talk to about myself or my problems |
| 74 | p2f1q33c_v3 | Num | 8 | 33cv3. I have someone who makes me feel appreciated |
| 75 | p2f1q33d_v3 | Num | 8 | 33dv3. I have someone to talk with when I have a bad day |
| 76 | p2f1q33a | Num | 8 | 33a. Think about how you felt in the past 7 days: I felt worthless. |
| 77 | p2f1q33b | Num | 8 | 33b. Think about how you felt in the past 7 days: I felt helpless. |
| 78 | p2f1q33c | Num | 8 | 33c. Think about how you felt in the past 7 days: I felt depressed. |
| 79 | p2f1q33d | Num | 8 | 33d. Think about how you felt in the past 7 days: I felt hopeless. |
| 80 | p2f1q33e | 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 | p2f1q33f | 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 | p2f1q33g | Num | 8 | 33g. Think about how you felt in the past 7 days: I felt tired. |
| 83 | p2f1q35a_v3 | Num | 8 | 35av3. In the past 7 days, how often did the following happen? I felt fearful |
| 84 | p2f1q35b_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 | p2f1q35c_v3 | Num | 8 | 35cv3. In the past 7 days, how often did the following happen? My worries overwhelmed me |

| Num | Variable | Type | Len | Label |
|-----|---------------|------|-----|--|
| 86 | p2f1q35d_v3 | Num | 8 | 35dv3. In the past 7 days, how often did the following happen? I felt uneasy |
| 87 | p2f1q34a | 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 | p2f1q34b | Num | 8 | 34b. In the past 7 days, how often did the following happen? My thinking was slow. |
| 89 | p2f1q34c | 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 | p2f1q34d | Num | 8 | 34d. In the past 7 days, how often did the following happen? I had trouble concentrating. |
| 91 | p2f1q35a | 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 | p2f1q35b | 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 | p2f1q35c | 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 | p2f1q35d | Num | 8 | 35d. How much difficulty do you currently have doing the following things? Learning new tasks or instructions? |
| 95 | p2f1q36a | Num | 8 | 35a. How much did you rely on others to take care of you because of your health? |
| 96 | p2f1q36b | Num | 8 | 35b. How much did your health make it hard for you to do things with your friends? |
| 97 | p2f1q39a_v3 | Num | 8 | 39av3. In the past month, please describe how often... I feel alone and apart from others |
| 98 | p2f1q39b_v3 | Num | 8 | 39bv3. In the past month, please describe how often... I feel left out |
| 99 | p2f1q39c_v3 | Num | 8 | 39cv3. In the past month, please describe how often... I feel that I am no longer close to anyone |
| 100 | p2f1q39d_v3 | Num | 8 | 39dv3. In the past month, please describe how often... I feel alone |
| 101 | p2f1q39e_v3 | Num | 8 | 39ev3. In the past month, please describe how often... I feel lonely |
| 102 | p2f1q39f_v3 | Num | 8 | 39fv3. In the past month, please describe how often... I feel isolated from others |
| 103 | p2f1q40a_v3 | Num | 8 | 40av3. I tend to bounce back quickly after hard times |
| 104 | p2f1q40b_v3 | Num | 8 | 40bv3. I have a hard time making it through stressful events |
| 105 | p2f1q40c_v3 | Num | 8 | 40cv3. It does not take me long to recover from a stressful event |
| 106 | p2f1q40d_v3 | Num | 8 | 40dv3. It is hard for me to snap back when something bad happens |
| 107 | p2f1q40e_v3 | Num | 8 | 40ev3. I usually come through difficult times with little trouble |
| 108 | p2f1q40f_v3 | Num | 8 | 40fv3. I tend to take a long time to get over set-backs in my life |
| 109 | p2f1q41_1a_v3 | Num | 8 | 41av3. In general, how would you rate your physical health? |
| 110 | p2f1q41_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 | p2f1q37 | 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 | p2f1q38a | Num | 8 | 38a. I can follow directions when my doctor changes my medications. |
| 113 | p2f1q38b | Num | 8 | 38b. I can take my medication when there is a change in my usual day (unexpected things happen). |
| 114 | p2f1q38c | Num | 8 | 38c. I can manage my medication without help. |
| 115 | p2f1q38d | Num | 8 | 38d. I can list my medications, including the doses and schedule. |
| 116 | p2f1q39 | 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 | p2f1q40__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 | p2f1q40__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 | p2f1q40__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 | p2f1q40__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 | p2f1q40__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 | p2f1q40__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 | p2f1q40__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 | p2f1q40__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 | p2f1q40__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 | p2f1q40__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 | p2f1q40__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 | p2f1q40__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 | p2f1q40__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 | p2f1q46_v3 | Num | 8 | 58. How hard is it for you to pay for the very basics like food, housing, medical care, and heating? |
| 131 | p2f1q47_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) |

| Num | Variable | Type | Len | Label |
|-----|------------|------|-----|--|
| 37 | p3f2q12_1 | Num | 8 | 12. Monocytes Test results |
| 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 |

| Num | Variable | Type | Len | Label |
|-----|------------|------|-----|---|
| 76 | p3f2q26__1 | Num | 8 | 26. CRP (choice=NA) |
| 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 |

| Num | Variable | Type | Len | Label |
|-----|-----------------|------|-----|--|
| 115 | p3f2q38_2 | Num | 8 | 38. Total iron binding capacity (TIBC) Date of Most Recent |
| 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) |

| Num | Variable | Type | Len | Label |
|-----|------------|------|-----|---|
| 154 | p3f2q49_2 | Num | 8 | 49. Urine microscopic WBCs Date of Most Recent |
| 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? |

| Num | Variable | Type | Len | Label |
|-----|-----------------|------|-----|---|
| 37 | p3f4q12b_a | Num | 8 | 12a. Endari Start date |
| 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 |

| Num | Variable | Type | Len | Label |
|-----|------------|------|-----|--|
| 76 | p3f4q27_1 | Num | 8 | 28. OB/GYN Visit Date |
| 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 |

| Num | Variable | Type | Len | Label |
|-----|------------|------|-----|--|
| 115 | p3f4q42 | Num | 8 | 43. Acute chest syndrome |
| 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 |

| Num | Variable | Type | Len | Label |
|-----|------------|------|-----|---|
| 154 | p3f4q65b | Num | 8 | 65b. Brain MRI test Image available? |
| 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) |

| Num | Variable | Type | Len | Label |
|-----|--------------------|------|-----|--|
| 189 | p3f4q38R | Num | 8 | 39. Stroke (recoded) |
| 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 |

| Num | Variable | Type | Len | Label |
|-----|-------------|------|-----|---|
| 32 | p3f1q16l | Num | 8 | 16l. In the past 12 months, have you been newly diagnosed with skin ulcers |
| 33 | p3f1q17 | Num | 8 | 19. In the past 12 months, have you taken hydroxyurea? |
| 34 | p3f1q18 | Num | 8 | 20. Are you currently taking hydroxyurea? |
| 35 | p3f1q19 | Num | 8 | 21. In the past 12 months, what is the reason you discontinued or stopped taking hydroxyurea? |
| 36 | p3f1q20 | Num | 8 | 22. How many days did you take hydroxyurea in the PAST WEEK? |
| 37 | p3f1q21__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 | p3f1q21__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 | p3f1q21__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 | p3f1q21__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 | p3f1q21__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 | p3f1q21__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 | p3f1q21__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 | p3f1q21__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 | p3f1q21__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 | p3f1q21__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 | p3f1q22__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 | p3f1q22__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 | p3f1q22__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 | p3f1q22__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 | p3f1q22__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 | p3f1q22__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 | p3f1q22__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 | p3f1q22__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 | p3f1q22__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 | p3f1q22__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 | p3f1q23 | Num | 8 | 25. In the past 12 months, have you taken the drug called Endari (l-glutamine)? |
| 58 | p3f1q24 | Num | 8 | 26. Are you currently taking Endari? |
| 59 | p3f1q25 | 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 | p3f1q26 | Num | 8 | 28. How many days did you take Endari in the PAST WEEK? |
| 61 | p3f1q27__1 | Num | 8 | 29. In the last 12 months, what side effects have you experienced while you were taking Endari? No side effects |
| 62 | p3f1q27__2 | Num | 8 | 29. In the last 12 months, what side effects have you experienced while you were taking Endari? Nausea/vomiting |
| 63 | p3f1q27__3 | Num | 8 | 29. In the last 12 months, what side effects have you experienced while you were taking Endari? Stomach pain |
| 64 | p3f1q27__4 | Num | 8 | 29. In the last 12 months, what side effects have you experienced while you were taking Endari? Cough |
| 65 | p3f1q27__5 | Num | 8 | 29. In the last 12 months, what side effects have you experienced while you were taking Endari? Headaches or dizziness |
| 66 | p3f1q27__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 | p3f1q30_v2f4 | Num | 8 | 30. In the past 12 months, have you taken the drug called Adakveo (crizanlizumab)? |
| 68 | p3f1q31_v2f4 | Num | 8 | 31. Are you currently taking Adakveo? |
| 69 | p3f1q32_v2f4 | Num | 8 | 32. In the past 12 months, what is the reason you discontinued or stopped taking Adakveo? |
| 70 | p3f1q33_v2f4 | Num | 8 | 33. How many infusions of Adakveo have you missed or rescheduled in the PAST 6 MONTHS? |
| 71 | p3f1q34_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 | p3f1q34_v2f4__2 | Num | 8 | 34. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Fever |
| 73 | p3f1q34_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 | p3f1q34_v2f4__4 | Num | 8 | 34. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Nausea |
| 75 | p3f1q34_v2f4__5 | Num | 8 | 34. In the last 12 months, what side effects have you experienced while you were taking Adakveo? Vomiting |
| 76 | p3f1q34_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 | p3f1q34_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 | p3f1q34_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 | p3f1q35_v2f4 | Num | 8 | 35. In the past 12 months, have you taken the drug called Oxbryta (voxelotor)? |
| 80 | p3f1q36_v2f4 | Num | 8 | 36. Are you currently taking Oxbryta? |
| 81 | p3f1q38_v2f4 | Num | 8 | 38. How many days did you take Oxbryta in the PAST WEEK? |
| 82 | p3f1q39_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 | p3f1q39_v2f4__2 | Num | 8 | 39. In the last 12 months, what side effects have you experienced while you were taking Oxbryta? Rash or hives |

| Num | Variable | Type | Len | Label |
|-----|-----------------|------|-----|--|
| 84 | p3flq39_v2f4__3 | Num | 8 | 39. In the last 12 months, what side effects have you experienced while you were taking Oxbryta? Headache |
| 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? |

| Num | Variable | Type | Len | Label |
|-----|---------------|------|-----|--|
| 119 | p3flq39a_v3_2 | Num | 8 | 39av3. I feel alone and apart from others |
| 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 | p3f1q40__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 | p3f1q40__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 | p3f1q40__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 | p3f1q40__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 | p3f1q40__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 | p3f1q40__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 | p3f1q46_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 | p3f1q47_v3_2 | Num | 8 | 59. Did you lose your health insurance in the past year? |
| 154 | p3f1q48_a1_v3_2 | Num | 8 | 48av3_2. Experienced discrimination because of your race, ethnicity, or color in any of these situation: at school? |
| 155 | p3f1q48_a2_v3_2 | Num | 8 | 48av3_2. How many times did this happen in the past 12 months? |
| 156 | p3f1q48_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 | p3f1q48_b2_v3_2 | Num | 8 | 48bv3_2. How many times did this happen in the past 12 months? |
| 158 | p3f1q48_c1_v3_2 | Num | 8 | 48cv3_2. Experienced discrimination because of your race, ethnicity, or color in any of these situation: at work? |
| 159 | p3f1q48_c2_v3_2 | Num | 8 | 48cv3_2. How many times did this happen in the past 12 months? |
| 160 | p3f1q48_d1_v3_2 | Num | 8 | 48dv3_2. Experienced discrimination because of your race, ethnicity, or color in any of these situation: getting housing? |
| 161 | p3f1q48_d2_v3_2 | Num | 8 | 48dv3_2. How many times did this happen in the past 12 months? |
| 162 | p3f1q48_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 | p3f1q48_e2_v3_2 | Num | 8 | 48ev3_2. How many times did this happen in the past 12 months? |
| 164 | p3f1q48_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 | p3f1q48_f2_v3_2 | Num | 8 | 48fv3_2. How many times did this happen in the past 12 months? |
| 166 | p3f1q48_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 | p3f1q48_g2_v3_2 | Num | 8 | 48gv3_2. How many times did this happen in the past 12 months? |
| 168 | p3f1q48_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 | p3f1q48_h2_v3_2 | Num | 8 | 48hv3_2. How many times did this happen in the past 12 months? |
| 170 | p3f1q48_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 | p3f1q48_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_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 | p3f1q45_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 | p3f1q45_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 | p3f1q45_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 | p3f1q45_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 | p3f1q45_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 | p3f1q45_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 | p3f1q45_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 | p3f1q46_v3 | Num | 8 | 58. How hard is it for you to pay for the very basics like food, housing, medical care, and heating? |
| 154 | p3f1q47_v3 | Num | 8 | 59. Did you lose your health insurance in the past year? |
| 155 | p3f1q48_a1_v3 | Num | 8 | 48av3. Experienced discrimination because of your race, ethnicity, or color in any of these situation: at school? |
| 156 | p3f1q48_a2_v3 | Num | 8 | 48av3. How many times did this happen in the past 12 months? |
| 157 | p3f1q48_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 | p3f1q48_b2_v3 | Num | 8 | 48bv3. How many times did this happen in the past 12 months? |
| 159 | p3f1q48_c1_v3 | Num | 8 | 48cv3. Experienced discrimination because of your race, ethnicity, or color in any of these situation: at work? |
| 160 | p3f1q48_c2_v3 | Num | 8 | 48cv3. How many times did this happen in the past 12 months? |
| 161 | p3f1q48_d1_v3 | Num | 8 | 48dv3. Experienced discrimination because of your race, ethnicity, or color in any of these situation: getting housing? |
| 162 | p3f1q48_d2_v3 | Num | 8 | 48dv3. How many times did this happen in the past 12 months? |
| 163 | p3f1q48_e1_v3 | Num | 8 | 48ev3. Experienced discrimination because of your race, ethnicity, or color in any of these situation: getting medical care? |
| 164 | p3f1q48_e2_v3 | Num | 8 | 48ev3. How many times did this happen in the past 12 months? |
| 165 | p3f1q48_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 | p3f1q48_f2_v3 | Num | 8 | 48fv3. How many times did this happen in the past 12 months? |
| 167 | p3f1q48_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 | p3f1q48_g2_v3 | Num | 8 | 48gv3. How many times did this happen in the past 12 months? |
| 169 | p3f1q48_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 | p3f1q48_h2_v3 | Num | 8 | 48hv3. How many times did this happen in the past 12 months? |
| 171 | p3f1q48_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 | p3f1q48_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 | p3f1q45_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 | p3f1q45_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 | p3f1q45_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 | p3f1q45_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 | p3f1q45_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 | p3f1q45_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 | p3f1q46_v3v4 | Num | 8 | 58. How hard is it for you to pay for the very basics like food, housing, medical care, and heating? |
| 150 | p3f1q47_v3v4 | Num | 8 | 59. Did you lose your health insurance in the past year? |
| 151 | p3f1q48_a1_v3v4 | Num | 8 | 48av3. Experienced discrimination because of your race, ethnicity, or color in any of these situation: at school? |
| 152 | p3f1q48_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 | p3f1q48_c1_v3v4 | Num | 8 | 48cv3. Experienced discrimination because of your race, ethnicity, or color in any of these situation: at work? |
| 154 | p3f1q48_d1_v3v4 | Num | 8 | 48dv3. Experienced discrimination because of your race, ethnicity, or color in any of these situation: getting housing? |
| 155 | p3f1q48_e1_v3v4 | Num | 8 | 48ev3. Experienced discrimination because of your race, ethnicity, or color in any of these situation: getting medical care? |
| 156 | p3f1q48_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 | p3f1q48_f2_v3v4 | Num | 8 | 48fv3. How many times did this happen in the past 12 months? |
| 158 | p3f1q48_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 | p3f1q48_g2_v3v4 | Num | 8 | 48gv3. How many times did this happen in the past 12 months? |
| 160 | p3f1q48_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 | p3f1q48_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) |

| Num | Variable | Type | Len | Label |
|-----|------------|------|-----|---|
| 37 | p1f2q12_1 | Num | 8 | 12. Monocytes Test results |
| 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 |

| Num | Variable | Type | Len | Label |
|-----|------------|------|-----|--|
| 76 | p1f2q25__1 | Num | 8 | 25. Fasting Blood Glucose (choice=NA) |
| 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 |

| Num | Variable | Type | Len | Label |
|-----|-----------------|------|-----|--|
| 115 | p1f2q37_2 | Num | 8 | 37. Serum iron Date of Most Recent |
| 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) |

| Num | Variable | Type | Len | Label |
|-----|-----------------|------|-----|--|
| 154 | p1f2q49_1r | Num | 8 | 49. Urine microscopic WBCs Test results |
| 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 |

| Num | Variable | Type | Len | Label |
|-----|------------|------|-----|---|
| 37 | p1flq15__1 | Num | 8 | 15. Most recent visit to Acute Pain/Infusion Center (not admitted) =Not in record |
| 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 |

| Num | Variable | Type | Len | Label |
|-----|------------|------|-----|--|
| 75 | p1flq30__1 | Num | 8 | 30. Transfusion episodic, exchange =None |
| 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) |

| Num | Variable | Type | Len | Label |
|-----|------------|------|-----|---|
| 114 | p1flq38_1 | Num | 8 | 38. Stroke age |
| 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) |

| Num | Variable | Type | Len | Label |
|-----|------------|------|-----|--|
| 153 | p1flq45_1 | Num | 8 | 45. Splenomegaly age |
| 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) |

| Num | Variable | Type | Len | Label |
|-----|------------|------|-----|---|
| 192 | p1flq52_1 | Num | 8 | 52. Multi-organ failure age |
| 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) |

| Num | Variable | Type | Len | Label |
|-----|------------------|------|-----|---|
| 231 | p1flq59_1 | Num | 8 | 59. Anxiety age |
| 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 |

| Num | Variable | Type | Len | Label |
|-----|------------|------|-----|---|
| 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 |
| 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 |

| Num | Variable | Type | Len | Label |
|-----|------------------|------|-----|--|
| 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. |
| 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 |

| Num | Variable | Type | Len | Label |
|-----|------------------|------|-----|--|
| 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) |
| 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 |

| Num | Variable | Type | Len | Label |
|-----|------------------|------|-----|--|
| 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 |
| 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) |