

Sickle Cell Research Project

Codebook for dataset

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Department Name

Institution Name

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q0

Variable Type: character

Interval:

Range of Missing Values: Not Applicable

Question: Visit Date

Label	Frequency
Not Applicable	4 (14.8%)

Valid	Invalid	Start	End	Time Zone	Format
23	6	2022-08-19	2022-09-02	UTC	YYYY-MM-DD

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q1

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question: Sex

Value	Label	Frequency	Valid %
0	Female	23 (79.3%)	79.3%
1	Male	6 (20.7%)	20.7%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	0	0	0	0	1	0

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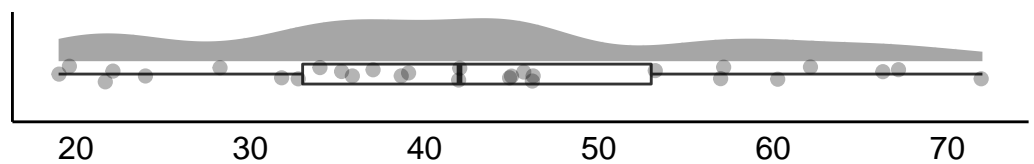
q2

Variable Type: numeric

Interval:

Range of Missing Values:

Question: Age



Valid	Invalid	Min	Q1	Median	Q3	Max
29	0	19	33	42	53	72

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q3

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question: Ethnicity

Value	Label	Frequency	Valid %
2	Afro-Guyanese/Black	19 (65.5%)	65.5%
7	Mixed	10 (34.5%)	34.5%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	2	2	2	7	7	2

q4

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question: In which region do you live?

Value	Label	Frequency	Valid %
3	Region 3	9 (31%)	31%
4	Region 4	16 (55.2%)	55.2%
7	Region 7	1 (3.4%)	3.4%
10	Region 10	3 (10.3%)	10.3%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	3	3	4	4	10	4

q5

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question: Highest Level of Education

Value	Label	Frequency	Valid %
3	Secondary (incomplete)	5 (17.2%)	17.2%
4	Secondary	10 (34.5%)	34.5%
5	Post-secondary/technical	8 (27.6%)	27.6%
6	University (ongoing)	2 (6.9%)	6.9%
7	University	4 (13.8%)	13.8%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	3	4	4	5	7	4

q6

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question: Marital Status

Value	Label	Frequency	Valid %
1	Single	10 (34.5%)	34.5%
3	Married	12 (41.4%)	41.4%
4	Divorced	3 (10.3%)	10.3%
5	Widow	4 (13.8%)	13.8%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	1	1	3	3	5	3

q7

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question: What is your employment status?

Value	Label	Frequency	Valid %
1	Student	2 (6.9%)	6.9%
2	Unemployed	1 (3.4%)	3.4%
3	Self-employed	8 (27.6%)	27.6%
4	Employed	14 (48.3%)	48.3%
6	Pensioner	4 (13.8%)	13.8%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	1	3	4	4	6	4

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q8

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question: How many children do you care for?

Value	Label	Frequency	Valid %
1	1	9 (31%)	31%
2	2	5 (17.2%)	17.2%
3	3	4 (13.8%)	13.8%
4	4	5 (17.2%)	17.2%
5	5 or more	6 (20.7%)	20.7%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	1	1	3	4	5	1

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q9

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question: Do you care for more than one child with SCD?

Value	Label	Frequency	Valid %
0	No	25 (86.2%)	86.2%
1	Yes	4 (13.8%)	13.8%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	0	0	0	0	1	0

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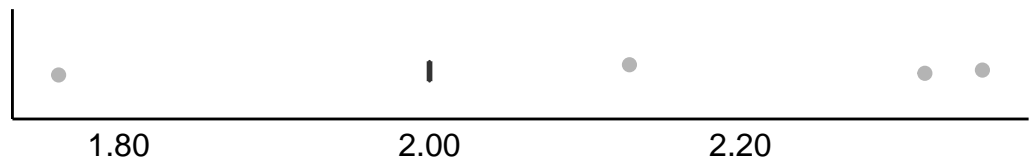
q9a

Variable Type: numeric

Interval:

Range of Missing Values: -3

Question: If yes (q9), please specify how many



Value	Label	Frequency	Valid %
-3	Not Applicable	25 (86.2%)	-

Valid	Invalid	Min	Q1	Median	Q3	Max
4	25	2	2	2	2	2

,

q10

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question: What is your relationship to the child with SCD?

Value	Label	Frequency	Valid %
1	Parent	11 (37.9%)	37.9%
2	Sibling	3 (10.3%)	10.3%
3	Aunt/Uncle	7 (24.1%)	24.1%
4	Grandparent	6 (20.7%)	20.7%
5	Cousin	2 (6.9%)	6.9%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	1	1	3	4	5	1

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q10a

Variable Type: character

Interval:

Range of Missing Values:

Question: If other, please specify

Label		Frequency	Valid %
Valid	Invalid	Mode	Unaccounted
0	29	NA	29

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q11

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question: Are you the person or one of the persons who usually takes care of the child with SCD?

Value	Label	Frequency	Valid %
1	Yes	29 (100%)	100%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	1	1	1	1	1	1

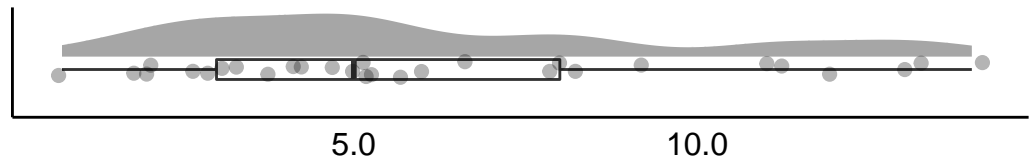
q12

Variable Type: numeric

Interval:

Range of Missing Values:

Question: How long have you been caring for the child with SCD?



Valid	Invalid	Min	Q1	Median	Q3	Max
29	0	0.75	3	5	8	14

q13

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question: How long has your child been diagnosed with SCD?

Value	Label	Frequency	Valid %
1	Less than 1 year	1 (3.4%)	3.4%
2	1-5 years	9 (31%)	31%
3	5-10 years	1 (3.4%)	3.4%
4	6-10 years	10 (34.5%)	34.5%
5	10-15 years	8 (27.6%)	27.6%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	1	2	4	5	5	4

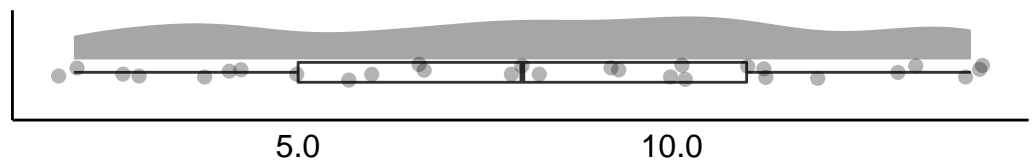
q14

Variable Type: numeric

Interval:

Range of Missing Values:

Question: What is the age of the child with SCD?



Valid	Invalid	Min	Q1	Median	Q3	Max
29	0	2	5	8	11	14

q15

Variable Type: numeric
Interval: discrete
Range of Missing Values:
Question:

What is the sex of the child with SCD?

Value	Label	Frequency	Valid %
0	Female	15 (51.7%)	51.7%
1	Male	14 (48.3%)	48.3%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	0	0	0	1	1	0

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q16_1

Variable Type: numeric
Interval: discrete
Range of Missing Values:
Question:

What forms of support do you receive from other members in your household/family to assist in the care of your child with SCD?: Financial

Value	Label	Frequency	Valid %
0	No	13 (44.8%)	44.8%
1	Yes	16 (55.2%)	55.2%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	0	0	1	1	1	1

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q16_2

Variable Type: numeric
Interval: discrete
Range of Missing Values:
Question:

What forms of support do you receive from other members in your household/family to assist in the care of your child with SCD?: Emotional

Value	Label	Frequency	Valid %
0	No	11 (37.9%)	37.9%
1	Yes	18 (62.1%)	62.1%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	0	0	1	1	1	1

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q16_3

Variable Type: numeric
Interval: discrete
Range of Missing Values:
Question:

What forms of support do you receive from other members in your household/family to assist in the care of your child with SCD?: Physical (e.g. Transportation, assistance with chores)

Value	Label	Frequency	Valid %
0	No	11 (37.9%)	37.9%
1	Yes	18 (62.1%)	62.1%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	7	0	1	1	1	1

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q16_4

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question: What forms of support do you receive from other members in your household/family to assist in the care of your child with SCD?: Resource or information sharing

Value	Label	Frequency	Valid %
0	No	18 (62.1%)	62.1%
1	Yes	11 (37.9%)	37.9%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	0	0	0	1	1	0

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q16_5

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question: What forms of support do you receive from other members in your household/family to assist in the care of your child with SCD?: Other

Value	Label					Frequency	Valid %
0	No					29 (100%)	100%
Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	0	0	0	0	0	0

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q16_6

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question: What forms of support do you receive from other members in your household/family to assist in the care of your child with SCD?: I do not receive support

Value	Label	Frequency	Valid %
0	No	26 (89.7%)	89.7%
1	Yes	3 (10.3%)	10.3%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	0	0	0	0	1	0

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q16a

Variable Type: character

Interval:

Range of Missing Values: Not Applicable

Question: If other, please specify

Label	Frequency	Valid %
Not Applicable	29 (100%)	-
Valid	Invalid	Mode
0	29	NA

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q17

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question: What is your child's SCD Genotype?

Value	Label	Frequency	Valid %
1	SS Disease	12 (41.4%)	41.4%
6	Unsure	17 (58.6%)	58.6%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	1	1	6	6	6	6

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q17a

Variable Type: character

Interval:

Range of Missing Values: Not Applicable

Question: If other variant is selected, then please specify the Genotype

Label	Frequency	Valid %
Not Applicable	29 (100%)	-
Valid	Invalid	Mode
0	29	NA

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q18

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question: Hydroxyurea is one of the medications that my child/children use

Value	Label	Frequency	Valid %
0	No	13 (44.8%)	44.8%
1	Yes	13 (44.8%)	44.8%
2	Unsure	3 (10.3%)	10.3%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	0	0	1	1	2	0,1

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q18a

Variable Type: numeric

Interval: discrete

Range of Missing Values: -3

Question: If yes, what is your frequency of use over the last (month)?

Value	Label	Frequency	Valid %				
-3	Not Applicable	16 (55.2%)	-				
1	As prescribed by my doctor	13 (44.8%)	100%				
Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
13	16	1	1	1	1	1	1

q18b

Variable Type: character

Interval:

Range of Missing Values: Not Applicable

Question: If do not used as prescribed is selected, please describe how often you use the drug

Label	Frequency	Valid %
Not Applicable	29 (100%)	-
Valid	Invalid	Mode
0	29	NA

q19

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question: In the last 6 months, how many times did you visit an emergency room because your child had a sickle cell painful event, and then was discharged home?

Value	Label	Frequency	Valid %
0	0	10 (34.5%)	34.5%
1	1	5 (17.2%)	17.2%
2	2	7 (24.1%)	24.1%
3	3	3 (10.3%)	10.3%
4	4 or more	4 (13.8%)	13.8%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	0	0	1	2	4	0

q20

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question: In the last 12 months, how many times was your child admitted to a hospital because of a sickle cell painful event?

Value	Label	Frequency	Valid %
0	0	18 (64.3%)	64.3%
1	1	9 (32.1%)	32.1%
4	4 or more	1 (3.6%)	3.6%

Valid	Invalid	Min	Q1	Median	Q3	Max	NA's
28	1	0	0	0	1	4	1

q21

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question: Number of pain episodes your child experienced in the last 6 months?

Value	Label	Frequency	Valid %
0	Less than 4	20 (74.1%)	74.1%
1	4 or more	7 (25.9%)	25.9%

Valid	Invalid	Min	Q1	Median	Q3	Max	NA's	M
27	2	0	0	0	0.5	1	2	0

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q22

Variable Type: numeric

Interval: discrete

Range of Missing Values: -3

Question: How long did your child miss school for due to pain in the last 6 months?

Value	Label	Frequency	Valid %
-3	Not Applicable	7 (24.1%)	-
0	Less than 1 week	14 (48.3%)	63.6%
1	More than 1 week	8 (27.6%)	36.4%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
22	7	0	0	0	1	1	0

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q23_1

Variable Type: numeric

Interval: discrete

Range of Missing Values: -3

Question: My child has trouble participating in sports activities or exercise~

Value	Label	Frequency	Valid %
-3	Not Applicable	6 (20.7%)	-
0	Never	8 (27.6%)	34.8%
1	Almost Never	3 (10.3%)	13%
2	Sometimes	9 (31%)	39.1%
3	Often	2 (6.9%)	8.7%
4	Almost Always	1 (3.4%)	4.3%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
23	6	0	0	2	2	4	2

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q23_2

Variable Type: numeric

Interval: discrete

Range of Missing Values: -3

Question: My child has trouble taking a bath or shower by him or herself

Value	Label	Frequency	Valid %
-3	Not Applicable	5 (17.2%)	-
0	Never	15 (51.7%)	62.5%
1	Almost Never	3 (10.3%)	12.5%
2	Sometimes	4 (13.8%)	16.7%
4	Almost Always	2 (6.9%)	8.3%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
24	5	0	0	0	1.25	4	0

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q23_3

Variable Type: numeric
Interval: discrete
Range of Missing Values: -3
Question: My child has trouble doing chores around the house

Value	Label	Frequency	Valid %
-3	Not Applicable	7 (24.1%)	-
0	Never	11 (37.9%)	50%
1	Almost Never	4 (13.8%)	18.2%
2	Sometimes	5 (17.2%)	22.7%
3	Often	2 (6.9%)	9.1%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
22	7	0	0	0.5	2	3	0

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q23_4

Variable Type: numeric
Interval: discrete
Range of Missing Values:
Question: My child constantly in pain

Value	Label	Frequency	Valid %
1	Almost Never	6 (20.7%)	20.7%
2	Sometimes	11 (37.9%)	37.9%
3	Often	5 (17.2%)	17.2%
4	Almost Always	7 (24.1%)	24.1%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	1	2	2	3	4	2

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q23_5

Variable Type: numeric
Interval: discrete
Range of Missing Values:
Question: My child constantly has low energy level

Value	Label	Frequency	Valid %
0	Never	4 (13.8%)	13.8%
1	Almost Never	4 (13.8%)	13.8%
2	Sometimes	16 (55.2%)	55.2%
3	Often	2 (6.9%)	6.9%
4	Almost Always	3 (10.3%)	10.3%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	0	1	2	2	4	2

q24_1

Variable Type: numeric
Interval: discrete
Range of Missing Values:
Question: My child is constantly afraid or scared

Value	Label	Frequency	Valid %
0	Never	12 (41.4%)	41.4%
1	Almost Never	3 (10.3%)	10.3%
2	Sometimes	13 (44.8%)	44.8%
4	Almost Always	1 (3.4%)	3.4%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	0	0	1	2	4	2

q24_2

Variable Type: numeric
Interval: discrete
Range of Missing Values:
Question: My child is constantly sad

Value	Label	Frequency	Valid %
0	Never	6 (20.7%)	20.7%
1	Almost Never	7 (24.1%)	24.1%
2	Sometimes	15 (51.7%)	51.7%
4	Almost Always	1 (3.4%)	3.4%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	0	1	2	2	4	2

q24_3

Variable Type: numeric
Interval: discrete
Range of Missing Values:
Question: My child is constantly angry

Value	Label	Frequency	Valid %
0	Never	24 (82.8%)	82.8%
1	Almost Never	1 (3.4%)	3.4%
2	Sometimes	4 (13.8%)	13.8%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	0	0	0	0	2	0

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q24_4

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question: My child has trouble sleeping

Value	Label	Frequency	Valid %
0	Never	12 (41.4%)	41.4%
1	Almost Never	2 (6.9%)	6.9%
2	Sometimes	6 (20.7%)	20.7%
3	Often	9 (31%)	31%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	0	0	2	3	3	0

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q24_5

Variable Type: numeric

Interval: discrete

Range of Missing Values: -3

Question: My child spends time worrying about what will happen to him or herself

Value	Label	Frequency	Valid %
-3	Not Applicable	5 (17.2%)	-
0	Never	19 (65.5%)	79.2%
1	Almost Never	2 (6.9%)	8.3%
2	Sometimes	3 (10.3%)	12.5%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
24	5	0	0	0	0	2	0

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q25_1

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question: My child has trouble getting along with other children

Value	Label	Frequency	Valid %
0	Never	19 (65.5%)	65.5%
1	Almost Never	1 (3.4%)	3.4%
2	Sometimes	4 (13.8%)	13.8%
3	Often	4 (13.8%)	13.8%
4	Almost Always	1 (3.4%)	3.4%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	0	0	0	2	4	0

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q25_2

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question:	My child has trouble with other kids not wanting to be his or her friend						
Value	Label	Frequency		Valid %			
0	Never	23 (79.3%)		79.3%			
2	Sometimes	5 (17.2%)		17.2%			
4	Almost Always	1 (3.4%)		3.4%			
Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	0	0	0	0	4	0

q25_3

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question:	My child gets teased by other children						
Value	Label	Frequency		Valid %			
0	Never	26 (89.7%)		89.7%			
2	Sometimes	3 (10.3%)		10.3%			
Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	0	0	0	0	2	0

q25_4

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question:	My child has trouble doing thing that other children his or her age can do						
Value	Label	Frequency		Valid %			
0	Never	6 (20.7%)		20.7%			
1	Almost Never	9 (31%)		31%			
2	Sometimes	6 (20.7%)		20.7%			
3	Often	6 (20.7%)		20.7%			
4	Almost Always	2 (6.9%)		6.9%			
Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	0	1	1	3	4	1

q25_5

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question:	My child has trouble keeping up when playing with other children						
Value	Label	Frequency		Valid %			
0	Never	5 (17.2%)		17.2%			
1	Almost Never	8 (27.6%)		27.6%			
2	Sometimes	4 (13.8%)		13.8%			
3	Often	8 (27.6%)		27.6%			
4	Almost Always	4 (13.8%)		13.8%			
Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	15 ⁰	1	2	3	4	1,3

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q26_1

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question: My child has trouble paying attention in class

Value	Label	Frequency	Valid %
0	Never	4 (13.8%)	13.8%
2	Sometimes	16 (55.2%)	55.2%
3	Often	6 (20.7%)	20.7%
4	Almost Always	3 (10.3%)	10.3%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	0	2	2	3	4	2

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q26_2

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question: My child has trouble remembering things

Value	Label	Frequency	Valid %
0	Never	1 (3.4%)	3.4%
1	Almost Never	1 (3.4%)	3.4%
2	Sometimes	13 (44.8%)	44.8%
3	Often	8 (27.6%)	27.6%
4	Almost Always	6 (20.7%)	20.7%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	0	2	2	3	4	2

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q26_3

Variable Type: numeric

Interval: discrete

Range of Missing Values: -3

Question: My child has trouble keeping up with schoolwork

Value	Label	Frequency	Valid %
-3	Not Applicable	6 (20.7%)	-
0	Never	3 (10.3%)	13%
1	Almost Never	9 (31%)	39.1%
2	Sometimes	5 (17.2%)	21.7%
3	Often	6 (20.7%)	26.1%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
23	6	0	1	1	2.5	3	1

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q26_4

Variable Type: numeric

Interval: discrete

Range of Missing Values:

-3

Question:

My child misses school because of not feeling well

Value	Label	Frequency	Valid %
-3	Not Applicable	6 (20.7%)	-
0	Never	4 (13.8%)	17.4%
1	Almost Never	7 (24.1%)	30.4%
2	Sometimes	7 (24.1%)	30.4%
3	Often	5 (17.2%)	21.7%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
23	6	0	1	2	2	3	2,1

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q26_5

Variable Type:

numeric

Interval:

discrete

Range of Missing Values:

-3

Question:

My child misses school to visit the Doctor or the Hospital

Value	Label	Frequency	Valid %
-3	Not Applicable	6 (20.7%)	-
0	Never	3 (10.3%)	13%
1	Almost Never	15 (51.7%)	65.2%
2	Sometimes	4 (13.8%)	17.4%
4	Almost Always	1 (3.4%)	4.3%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
23	6	0	1	1	1	4	1

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q27_1

Variable Type:

numeric

Interval:

discrete

Range of Missing Values:

Question:

Transportation to attend clinic/ hospital visits is an issue

Value	Label	Frequency	Valid %
0	Never	4 (13.8%)	13.8%
1	Almost Never	8 (27.6%)	27.6%
2	Sometimes	11 (37.9%)	37.9%
3	Often	4 (13.8%)	13.8%
4	Almost Always	2 (6.9%)	6.9%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	0	1	2	2	4	2

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q27_2

Variable Type:

numeric

Interval:

discrete

Range of Missing Values:

Question:

I have to wait a long time before being seen in clinic

Value	Label	Frequency	Valid %
0	Never	11 (37.9%)	37.9%
1	Almost Never	8 (27.6%)	27.6%
2	Sometimes	6 (20.7%)	20.7%
3	Often	1 (3.4%)	3.4%
4	Almost Always	3 (10.3%)	10.3%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	0	0	1	2	4	0

q27_3

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question: Clinic visits are convenient to my and my child's schedule

Value	Label	Frequency	Valid %
0	Never	3 (10.3%)	10.3%
1	Almost Never	9 (31%)	31%
2	Sometimes	13 (44.8%)	44.8%
3	Often	4 (13.8%)	13.8%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	0	1	2	2	3	2

q27_4

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question: I understand how to navigate the hospital to access the care my child needs

Value	Label	Frequency	Valid %
3	Often	3 (10.3%)	10.3%
4	Almost Always	26 (89.7%)	89.7%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	3	4	4	4	4	4

q27_5

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question: I encounter impatient nurses/doctors during my clinic visits

Value	Label	Frequency	Valid %
0	Never	16 (55.2%)	55.2%
1	Almost Never	10 (34.5%)	34.5%
2	Sometimes	3 (10.3%)	10.3%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	0	0	0	1	2	0

q27_6

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question: I agree with the doctor's plan for treating my child

Value	Label	Frequency	Valid %
3	Often	1 (3.4%)	3.4%
4	Almost Always	28 (96.6%)	96.6%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	3	4	4	4	4	4

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q27_7

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question: The medication my child needs is available for free at clinic visits~

Value	Label	Frequency	Valid %
1	Almost Never	2 (6.9%)	6.9%
3	Often	6 (20.7%)	20.7%
4	Almost Always	21 (72.4%)	72.4%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	1	3	4	4	4	4

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q27_8

Variable Type: numeric

Interval: discrete

Range of Missing Values:

Question: I have ready access to medical care when my child is ill

Value	Label	Frequency	Valid %
2	Sometimes	1 (3.4%)	3.4%
3	Often	1 (3.4%)	3.4%
4	Almost Always	27 (93.1%)	93.1%

Valid	Invalid	Min	Q1	Median	Q3	Max	Mode
29	0	2	4	4	4	4	4

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q28

Variable Type: character

Interval:

Range of Missing Values:

Question: What other aspects of the health care system do you find difficult to deal with?

Label	Frequency	Valid %
Inadequate evaluation of children for secondary illnesses	1 (3.4%)	3.4%
Lab staff are sometimes difficult and unnecessarily complicated	1 (3.4%)	3.4%
Long wait at pharmacy	1 (3.4%)	3.4%
Long wait at Pharmacy	1 (3.4%)	3.4%
Long wait at the lab	1 (3.4%)	3.4%
Missing or unavailable blood test results	1 (3.4%)	3.4%
Nil	1 (3.4%)	3.4%
NiL	19 (65.5%)	65.5%
No classes available withing the health care setting to explain SCD in detail and what to expect	1 (3.4%)	3.4%
No clinics for SCD in region 10	1 (3.4%)	3.4%
There should be a better triage system for children in the Emergency room	1 (3.4%)	3.4%
Valid	Invalid	Mode
29	0	NiL

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q29

Variable Type: character

Interval:

Range of Missing Values:

Question: Are there any recommendations that you can suggest to health care providers that would help to to ease caring for your child with SCD?

Label	Frequency	Valid %
Availability of clinics within neighbourhood which can manage SCD	3 (10.3%)	10.3%
Conducting a more indepth evaluation of children as with developed countries	1 (3.4%)	3.4%
Have a separate smaller lab for pediatric clinics similar to the pharmacy	1 (3.4%)	3.4%
Intro9ducing a SCD clinic in Linden for easy access for frequent clinic visits	1 (3.4%)	3.4%
Lab should implement a better system that allows children to have some priority	1 (3.4%)	3.4%
NiL	16 (55.2%)	55.2%
Staff should be better trained in customer service	1 (3.4%)	3.4%
Telephone check ups	1 (3.4%)	3.4%
There should be support for parents of children with SCD especially newly diagnosed cases	1 (3.4%)	3.4%
Training for Lab staff in customer service	1 (3.4%)	3.4%
Two available windows at pharmacy	2 (6.9%)	6.9%

Valid	Invalid	Mode
29	0	NiL