#### BABY HUG FOLLOW-UP STUDY II

### **PedsQL**

PA	RII: II	DENTIFYING INF						
1.	Patier	nt's ID Number:	SUBJE0	CT_ID 	2. C	urrent Clinic:	SITE_ID	
3.	Patier	nt's Letter Code:		LETT	ER_CD			
4.	Visit D	Date:	 Month		<u> </u>		VISIT_DT	
			MONTH	Day		Year		
PA	RT II: F	FAMILY INFORM	ATION					
RE	LATION	NSHIP						
1.	What	is your relationsh	ip to this chile	d (please che	eck and/c	or circle)?		
	Fathe Grand Grand Guard Other		oster Father			RLTN_	RLTNSHP (1) (2) (3) (4) (5) (6)*	
2.	Inform	nation about the c	hild.					
	A.	Date of birth:		Month	 Day		 Year	BIRTH_DT
	В.	Child is:				Male (1)	Female (2)	SEX
	C.	Ethnic Group or	Race:				DACE	
		Black, Non-Hisp Asian or Pacific Hispanic White, Non-Hisp Native Americal Other *a. If Othe	Islander panic n or Alaskan	Native		RACE_C	(1) (2) (3) (4) (5) (6)*	
				ID Numbe	er	Visit		Seq
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#### 3. Information about mother: A. Marital status: MRTLST\_M Single (1) Married (2) (3) Separated Living with someone (4) Divorced (5)Widowed B. Highest level of education: EDU\_M 6<sup>th</sup> grade or less (1) 7<sup>th</sup>-9<sup>th</sup> grade or less (2) 9<sup>th</sup>-12<sup>th</sup> grade or less (3)High school graduate (4)Some college or certification course (5)College graduate Graduate or Professional Degree C. Occupation or Job Title: JOB M Information about father: Α. Marital status: MRTLST\_F Single (1) Married (2) Separated (3)Living with someone (4)Divorced (5)Widowed (6)B. Highest level of education: EDU F 6<sup>th</sup> grade or less (1) 7<sup>th</sup>-9<sup>th</sup> grade or less (2)9<sup>th</sup>-12<sup>th</sup> grade or less (3)High school graduate (4)Some college or certification course (5)College graduate Graduate or Professional Degree Occupation or Job Title: JOB\_F C.

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5.											
J.	Imp	act Sc	ale:								
	In th	ne past	t 6 months, has	your child							
	A.	cond	a chronic healt lition that has la feres with your	asted or is expe	ected to						
		*1.	If YES, what	is the name of	your chi	ld's chro	onic health	n condition	_	HC_NAME	
	In th	ne past	t 12 months, ha	s your child ha	ad						_
	B.	Any	overnight visits	to the hospital	?			OVNT_12N	Yes (1)*		
		*1.	If YES, how r	nany times?				OVNT_I	NUM		
		*2.	What was wr	ong?						OVNT_RSN	_
	C.	Any	Emergency Ro	om/Urgent Car	e Visits	?		ER_12M	Yes (1)*		
		*1.	If YES, how r	many times?				ER_	NUM		
		*2.	What was wr	ona?						ER_RSN	
											_
	In th	ne past	t 30 days							<u> </u>	_
	In th	How						ical or	.30р		_
		How ment	t 30 days many days did	your child mis	s from s	chool du	ıe to phys	ical or	30р		_
	D.	How ment How How	t 30 days… many days did tal health?	your child mis s your child sic your child nee	s from s ck in bed	chool du	ie to phys I to play?	ical or ABST_ SICK_:	.30D 30D to		
6.	D. E. F.	How ment How How phys	t 30 days many days did tal health? many days wa many days did	your child mis s your child sid your child nee nealth?	s from s k in bed ed somed	chool du	ie to phys I to play?	ical or ABST_ SICK_: n/her due	.30D 30D to		_
6.	D. E. F.	How ment How How phys	t 30 days many days did tal health? many days wa many days did ical or mental h	your child miss your child side your child need nealth?	s from s k in bed ed somed	chool du or too il	ie to phys I to play?	ical or  ABST_ SICK_: n/her due  CARE_	.30D 30D to 30D		-
6.	D. E. F.	How ment How How phys	t 30 days many days did tal health? many days wa many days did ical or mental h	your child miss s your child side the home?  If No, so how many day	s from s ck in bed ed some	chool du or too il one to ca	ie to phys I to play? are for hin	ical or  ABST_ SICK_: n/her due CARE_ WKOTSDHM	30D 30D to 30D Yes*		_
6.	D. E. F.	How ment How How phys	t 30 days many days did tal health? many days wa many days did ical or mental h egiver work outs	your child miss s your child side the home?  If No, so how many day or mental hear	s from s  ck in bed  ed some  skip to P  ys have  alth?	chool du one to ca	l to play? are for hin	ical or  ABST_ SICK_: n/her due CARE_:  WKOTSDHM	30D 30D to 30D Yes*		_
6.	D. E. F. Doe	How ment How How physes care  In the your In the	many days did tal health? many days wa many days did ical or mental h giver work outs e past 30 days, child's physica e past 30 days,	your child miss s your child side your child need nealth?  If No, so how many day or mental head has your child need the home?	s from s ck in bed ed some skip to P ys have alth? I's health	chool du or too il one to ca  Part III.  you misa n interfer  Never  (0)	le to phys I to play? are for hin sed from v ed with Almost Never (1)	ical or  ABST_ SICK_: n/her due CARE_:  WKOTSDHM  WORK due MSWK_ Some- times (2)	30D to 30D Yes*  to 30D  Yes*	No Almost Always (4)	RTII
6.	D. E. F. Doe	How ment How How physes care  In the your In the	many days did tal health? many days wa many days did ical or mental h giver work outs e past 30 days, child's physica e past 30 days,	your child miss s your child side your child need nealth?  If No, so how many day or mental head has your child need the home?	s from s ck in bed ed some skip to P ys have alth? I's health	chool du or too il one to ca  Part III.  you misa n interfer	I to play?  I to play?  are for hin  sed from ved with  Almost Never	ical or  ABST_ SICK_:  n/her due CARE_  WKOTSDHM  WORK due MSWK_ Some- times	30D to 30D Yes* to 30D Often	No Almost	RTII

#### PART III: GENERIC CORE SCALES

### 1. **Child** Report (Ages 8-12)

In the past one month, how much of a problem has this been for you...

			Never	Almost Never	Some- times	Often	Almost Always
١.	Abo	out my health and activities (problems with	1)				7 5
	1.	It is hard for me to walk more than one					
		block	(0)	(1)	(2)	(3)	(4)
	2.	It is hard for me to run	(0)	(1)	(2)	(3)	(4)
	3.	It is hard for me to do sports activity or	(-)	\ /		(-)	\ /
		exercise	(0)	(1)	(2)	(3)	(4)
	4.	It is hard for me to lift something heavy	(0)	(1)	(2)	(3)	(4)
	5.	It is hard for me to take a bath or	(-)			(-)	\ /
		shower by myself	(0)	(1)	(2)	(3)	(4)
	6.	It is hard for me to do chores around	(5)	( ' /	(-/	(0)	( · /
	•	the house	(0)	(1)	(2)	(3)	(4)
	7.	I hurt or ache	(0)	(1)	(2)	(3)	(4)
	8.	I have low energy	(0)	(1)	(2)	(3)	(4)
	<u> </u>	Thave let energy	(0)	(')	(-)	(0)	( ' /
3.	Abr	out my feelings (problems with)					
<u></u>	1.	I feel afraid or scared	(0)	(1)	(2)	(3)	(4)
	2.	I feel sad or blue	(0)	(1)	(2)	(3)	(4)
	3.	I feel angry	(0)	(1)	(2)	(3)	(4)
	4.	I have trouble sleeping	(0)	(1)	(2)	(3)	(4)
	5.	I worry about what will happen to me	(0)	(1)	(2)	(3)	(4)
	٥.	T worry about wriat will happen to me	(0)	(1)	(2)	(3)	(4)
).	Hov	w I get along with others (problems with)					
	1.	I have trouble getting along with other					
		kids	(0)	(1)	(2)	(3)	(4)
	2.	Other kids do not want to be my friend	(0)	(1)	(2)	(3)	(4)
	3.	Other kids tease me	(0)	(1)	(2)	(3)	(4)
	4.	I cannot do things that other kids my		, ,			, ,
		age can do	(0)	(1)	(2)	(3)	(4)
	5.	It is hard to keep up when I play with	` ′	` ,	` ′	` ′	. ,
		other kids	(0)	(1)	(2)	(3)	(4)
_	Λla				T		
J.		out school (problems with)	(0)	(4)	(0)	(2)	/ A \
	1.	It is hard to pay attention in class	(0)	(1)	(2)	(3)	(4)
	2.	I forget things	(0)	(1)	(2)	(3)	(4)
	3.	I have trouble keeping up with my	(0)	(4)	(0)	(0)	(4)
		schoolwork	(0)	(1)	(2)	(3)	(4)
	4.	I miss school because of not feeling	(0)	(4)	(6)	(6)	
		well	(0)	(1)	(2)	(3)	(4)
	5.	I miss school to go to the doctor or	/=:		(=)	(=)	
		hospital	(0)	(1)	(2)	(3)	(4)
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		ID Numbe	r	V	ารแ		seq

### 2. **Parent** Report (for Children Ages 8-12)

In the past one month, how much of a problem has your child had with...

			Never	Almost	Some-	Often	Almost	
Α.	Phy	sical functioning (problems with)		Never	times		Always	1
Λ.	1.	Walking more than one block	(0)	(1)	(2)	(3)	(4)	GPRPT_A1
	2.	Running	(0)	(1)	(2)	(3)	(4)	GPRPT_A1
	3.	Participating in sports activity or	(0)	(1)	(2)	(0)	(1)	GFRF1_AZ
	0.	exercise	(0)	(1)	(2)	(3)	(4)	GPRPT_A3
	4.	Lifting something heavy	(0)	(1)	(2)	(3)	(4)	GPRPT_A4
	5.	Taking a bath or shower by him or	(-)			(-)		
		herself	(0)	(1)	(2)	(3)	(4)	GPRPT_A5
	6.	Doing chores around the house	(0)	(1)	(2)	(3)	(4)	GPRPT_A6
	7.	Having hurts or aches	(0)	(1)	(2)	(3)	(4)	GPRPT_A7
	8.	Low energy level	(0)	(1)	(2)	(3)	(4)	GPRPT_A8
								<u>.                                      </u>
B.	Em	otional functioning (problems with)						
	1.	Feeling afraid or scared	(0)	(1)	(2)	(3)	(4)	GPRPT_B1
	2.	Feeling sad or blue	(0)	(1)	(2)	(3)	(4)	GPRPT_B2
	3.	Feeling angry	(0)	(1)	(2)	(3)	(4)	GPRPT_B3
	4.	Trouble sleeping	(0)	(1)	(2)	(3)	(4)	GPRPT_B4
	5.	Worrying about what will happen to						GPRPT_B5
		him or her	(0)	(1)	(2)	(3)	(4)	
			1	T		T	T	7
C.		cial functioning (problems with)	(2)	(4)	(5)	(2)	(4)	
	1.	Getting along with other children	(0)	(1)	(2)	(3)	(4)	GPRPT_C1
	2.	Other kids not wanting to be his or her	(0)	(1)	(2)	(3)	(4)	
		friend						GPRPT_C2
	3.	Getting teased by other children	(0)	(1)	(2)	(3)	(4)	GPRPT_C3
	4.	Not able to do things that other	(0)	(4)	(0)	(0)	(4)	
	_	children his or her age can do	(0)	(1)	(2)	(3)	(4)	GPRPT_C4
	5.	Keeping up when playing with other	(0)	(4)	(2)	(2)	(4)	_
		children	(0)	(1)	(2)	(3)	(4)	GPRPT_C5
D.	Sch	nool functioning (problems with)						1
<i>D</i> .	1.	Paying attention in class	(0)	(1)	(2)	(3)	(4)	GPRPT D1
	2.	Forgetting things	(0)	(1)	(2)	(3)	(4)	GPRPT_D1 GPRPT_D2
	3.	Keeping up with schoolwork	(0)	(1)	(2)	(3)	(4)	GPRPT_D2
	4.	Missing school because of not feeling	(0)	(1)	(2)	(0)	(+)	GPRP1_D3
	~.	well	(0)	(1)	(2)	(3)	(4)	GPRPT_D4
	5.	Missing school to go to the doctor or	(0)	\'/	\~)	(0)	(")	GERET_D4
	0.	hospital	(0)	(1)	(2)	(3)	(4)	GPRPT_D5
	1	Hoopital	. (~)	\'/	\-/	\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\	\'/	J 31 KI 1_D3

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### PART IV: FATIGUE SCALES

## 1. **Child** Report (Ages 8-12)

In the past one month, how much of a problem has this been for you...

			Never	Almost	Some-	Often	Almost	
				Never	times		Always	
A.	Ge	neral fatigue (problems with)						
	1.	I feel tired	(0)	(1)	(2)	(3)	(4)	FCRPT_A1
	2.	I feel physically weak (not strong)	(0)	(1)	(2)	(3)	(4)	FCRPT_A2
	3.	I feel too tired to do things that I like to						
		do	(0)	(1)	(2)	(3)	(4)	FCRPT_A3
	4.	I feel too tired to spend time with my						
		friends	(0)	(1)	(2)	(3)	(4)	FCRPT_A4
	5.	I have trouble finishing things	(0)	(1)	(2)	(3)	(4)	FCRPT_A5
	6.	I have trouble starting things	(0)	(1)	(2)	(3)	(4)	FCRPT_A6
								-
B.	Sle	ep/Rest fatigue (problems with)						
	1.	I sleep a lot	(0)	(1)	(2)	(3)	(4)	FCRPT_B1
	2.	It is hard for me to sleep through the						
		night	(0)	(1)	(2)	(3)	(4)	FCRPT_B2
	3.	I feel tired when I wake up in the						
		morning	(0)	(1)	(2)	(3)	(4)	FCRPT_B3
	4.	I rest a lot	(0)	(1)	(2)	(3)	(4)	FCRPT_B4
	5.	I take a lot of naps	(0)	(1)	(2)	(3)	(4)	FCRPT_B5
	6.	I spend a lot of time in bed	(0)	(1)	(2)	(3)	(4)	FCRPT_B6
								_
C.	Cog	gnitive fatigue (problems with)						
	1.	It is hard for me to keep my attention						
		on things	(0)	(1)	(2)	(3)	(4)	FCRPT_C1
	2.	It is hard for me to remember what						
		people tell me	(0)	(1)	(2)	(3)	(4)	FCRPT_C2
	3.	It is hard for me to remember what I						
		just heard	(0)	(1)	(2)	(3)	(4)	FCRPT_C3
	4.	It is hard for me to think quickly	(0)	(1)	(2)	(3)	(4)	FCRPT_C4
	5.	I have trouble remembering what I	, ,	, ,	` '	, ,	, ,	]
		was just thinking	(0)	(1)	(2)	(3)	(4)	FCRPT_C5
	6.	I have trouble remembering more than	, ,	, ,	, ,	, ,	, ,	_
		one thing at a time	(0)	(1)	(2)	(3)	(4)	FCRPT_C6

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# 2. **Parent** Report (Ages 8-12)

In the past one month, how much of a problem has this been for your child...

A. General fatigue (problems with)  1. Feeling tired (0) (1) (2) (3) (4) FPRPT_A1  2. Feeling physically weak (not strong) (0) (1) (2) (3) (4) FPRPT_A2  3. Feeling too tired to do things that he/she likes to do (0) (1) (2) (3) (4) FPRPT_A3  4. Feeling too tired to spend time with his/her friends (0) (1) (2) (3) (4) FPRPT_A3  5. Trouble finishing things (0) (1) (2) (3) (4) FPRPT_A5  6. Trouble starting things (0) (1) (2) (3) (4) FPRPT_A5  6. Trouble starting things (0) (1) (2) (3) (4) FPRPT_A5  FPRPT_A5  B. Sleep/Rest fatigue (problems with)  1. Sleeping a lot 2. Difficulty sleeping through the night (0) (1) (2) (3) (4) FPRPT_B1  FPRPT_B2  3. Feeling tired when he/she wakes up in the morning (0) (1) (2) (3) (4) FPRPT_B3  4. Resting a lot (0) (1) (2) (3) (4) FPRPT_B3  6. Spending a lot of naps (0) (1) (2) (3) (4) FPRPT_B4  5. Taking a lot of naps (0) (1) (2) (3) (4) FPRPT_B4  6. Spending a lot of time in bed (0) (1) (2) (3) (4) FPRPT_B5  FPRPT_B6  C. Cognitive fatigue (problems with)  1. Difficulty keeping his/her attention on things (0) (1) (2) (3) (4) FPRPT_C1  2. Difficulty remembering what he/she just heard (0) (1) (2) (3) (4) FPRPT_C3  4. Difficulty thinking quickly (0) (1) (2) (3) (4) FPRPT_C3  6. Trouble remembering what he/she was just thinking (0) (1) (2) (3) (4) FPRPT_C5  6. Trouble remembering more than one thing at a time (0) (1) (2) (3) (4) FPRPT_C5				Never	Almost	Some-	Often	Almost	]
1.   Feeling tired					Never	times		Always	
2. Feeling physically weak (not strong)	A.	Ge	neral fatigue (problems with)						
3. Feeling too tired to do things that he/she likes to do  4. Feeling too tired to spend time with his/her friends  5. Trouble finishing things  6. Trouble starting things  7. Trouble starting things  8. Sleep/Rest fatigue (problems with)  1. Sleeping a lot  2. Difficulty sleeping through the night  3. Feeling tired when he/she wakes up in the morning  4. Resting a lot  5. Taking a lot of naps  6. Spending a lot of time in bed  C. Cognitive fatigue (problems with)  1. Difficulty keeping his/her attention on things  2. Difficulty remembering what people tell him/her  3. Difficulty remembering what he/she just heard  4. Difficulty thinking quickly  6. Trouble remembering what he/she was just thinking  (0) (1) (2) (3) (4) FPRPT_B3  FPRPT_B4  FPRPT_B5  FPRPT_B5  FPRPT_B6  C. Cognitive fatigue (problems with)  (0) (1) (2) (3) (4) FPRPT_B6  FPRPT_B6  FPRPT_C1  FPRPT_C2  FPRPT_C2  FPRPT_C3  FPRPT_C3  FPRPT_C3  FPRPT_C4  FPRPT_C5  FPRPT_C5  FPRPT_C6		1.	Feeling tired	(0)	(1)	(2)	(3)	(4)	FPRPT_A1
he/she likes to do		2.	Feeling physically weak (not strong)	(0)	(1)	(2)	(3)	(4)	FPRPT_A2
4.   Feeling too tired to spend time with his/her friends   (0) (1) (2) (3) (4)   FPRPT_A4		3.	Feeling too tired to do things that						
his/her friends			he/she likes to do	(0)	(1)	(2)	(3)	(4)	FPRPT_A3
5.   Trouble finishing things   (0)   (1)   (2)   (3)   (4)		4.	Feeling too tired to spend time with						
B.   Sleep/Rest fatigue (problems with)   1.   Sleeping a lot   (0)   (1)   (2)   (3)   (4)   FPRPT_B1     2.   Difficulty sleeping through the night   (0)   (1)   (2)   (3)   (4)   FPRPT_B2     3.   Feeling tired when he/she wakes up in the morning   (0)   (1)   (2)   (3)   (4)   FPRPT_B2     4.   Resting a lot   (0)   (1)   (2)   (3)   (4)   FPRPT_B3     5.   Taking a lot of naps   (0)   (1)   (2)   (3)   (4)   FPRPT_B4     6.   Spending a lot of time in bed   (0)   (1)   (2)   (3)   (4)   FPRPT_B5     7.   C.   Cognitive fatigue (problems with)     (2)   (3)   (4)   FPRPT_B6     7.   Difficulty keeping his/her attention on things   (0)   (1)   (2)   (3)   (4)   FPRPT_C1     8.   Sleep/Rest fatigue (problems was part of the morning of t				(0)	(1)		(3)	(4)	FPRPT_A4
B. Sleep/Rest fatigue (problems with)  1. Sleeping a lot  2. Difficulty sleeping through the night  3. Feeling tired when he/she wakes up in the morning  4. Resting a lot  5. Taking a lot of naps  6. Spending a lot of time in bed  C. Cognitive fatigue (problems with)  1. Difficulty keeping his/her attention on things  2. Difficulty remembering what people tell him/her  3. Difficulty remembering what he/she just heard  4. Difficulty thinking quickly  5. Trouble remembering what he/she wakes up in the morning  (0) (1) (2) (3) (4) FPRPT_B3  (0) (1) (2) (3) (4) FPRPT_B5  (0) (1) (2) (3) (4) FPRPT_C1  (0) (1) (2) (3) (4) FPRPT_C2  (0) (1) (2) (3) (4) FPRPT_C2  (0) (1) (2) (3) (4) FPRPT_C3  (0) (1) (2) (3) (4) FPRPT_C3  (0) (1) (2) (3) (4) FPRPT_C3  (0) (1) (2) (3) (4) FPRPT_C4  (0) (1) (2) (3) (4) FPRPT_C4  (0) (1) (2) (3) (4) FPRPT_C5  (0) (1) (2) (3) (4) FPRPT_C5		5.		(0)	(1)	_ \ /	(3)	(4)	FPRPT_A5
1.   Sleeping a lot   (0) (1) (2) (3) (4)   FPRPT_B1		6.	Trouble starting things	(0)	(1)	(2)	(3)	(4)	FPRPT_A6
1.   Sleeping a lot   (0) (1) (2) (3) (4)   FPRPT_B1									_
2. Difficulty sleeping through the night (0) (1) (2) (3) (4) FPRPT_B2  3. Feeling tired when he/she wakes up in the morning (0) (1) (2) (3) (4) FPRPT_B3  4. Resting a lot (0) (1) (2) (3) (4) FPRPT_B4  5. Taking a lot of naps (0) (1) (2) (3) (4) FPRPT_B5  6. Spending a lot of time in bed (0) (1) (2) (3) (4) FPRPT_B5  C. Cognitive fatigue (problems with)  1. Difficulty keeping his/her attention on things (0) (1) (2) (3) (4) FPRPT_B6  C. Difficulty remembering what people tell him/her (0) (1) (2) (3) (4) FPRPT_C1  3. Difficulty remembering what he/she just heard (0) (1) (2) (3) (4) FPRPT_C3  4. Difficulty thinking quickly (0) (1) (2) (3) (4) FPRPT_C3  5. Trouble remembering what he/she was just thinking (0) (1) (2) (3) (4) FPRPT_C5  6. Trouble remembering more than one	B.	Sle							
3. Feeling tired when he/she wakes up in the morning (0) (1) (2) (3) (4) FPRPT_B3  4. Resting a lot (0) (1) (2) (3) (4) FPRPT_B4  5. Taking a lot of naps (0) (1) (2) (3) (4) FPRPT_B5  6. Spending a lot of time in bed (0) (1) (2) (3) (4) FPRPT_B6   C. Cognitive fatigue (problems with)  1. Difficulty keeping his/her attention on things (0) (1) (2) (3) (4) FPRPT_B6   C. Difficulty remembering what people tell him/her (0) (1) (2) (3) (4) FPRPT_C1  3. Difficulty remembering what he/she just heard (0) (1) (2) (3) (4) FPRPT_C3  4. Difficulty thinking quickly (0) (1) (2) (3) (4) FPRPT_C3  5. Trouble remembering what he/she was just thinking (0) (1) (2) (3) (4) FPRPT_C4  6. Trouble remembering more than one		1.	Sleeping a lot	(0)	(1)	(2)	(3)	(4)	FPRPT_B1
the morning (0) (1) (2) (3) (4) FPRPT_B3  4. Resting a lot (0) (1) (2) (3) (4) FPRPT_B4  5. Taking a lot of naps (0) (1) (2) (3) (4) FPRPT_B5  6. Spending a lot of time in bed (0) (1) (2) (3) (4) FPRPT_B5  C. Cognitive fatigue (problems with)  1. Difficulty keeping his/her attention on things (0) (1) (2) (3) (4) FPRPT_C1  2. Difficulty remembering what people tell him/her (0) (1) (2) (3) (4) FPRPT_C2  3. Difficulty remembering what he/she just heard (0) (1) (2) (3) (4) FPRPT_C3  4. Difficulty thinking quickly (0) (1) (2) (3) (4) FPRPT_C4  5. Trouble remembering what he/she was just thinking (0) (1) (2) (3) (4) FPRPT_C5  6. Trouble remembering more than one		2.	Difficulty sleeping through the night	(0)	(1)	(2)	(3)	(4)	FPRPT_B2
4. Resting a lot       (0)       (1)       (2)       (3)       (4)       FPRPT_B4         5. Taking a lot of naps       (0)       (1)       (2)       (3)       (4)       FPRPT_B5         6. Spending a lot of time in bed       (0)       (1)       (2)       (3)       (4)       FPRPT_B5         C. Cognitive fatigue (problems with)       (0)       (1)       (2)       (3)       (4)       FPRPT_B6         To Difficulty keeping his/her attention on things       (0)       (1)       (2)       (3)       (4)       FPRPT_C1         2. Difficulty remembering what people tell him/her       (0)       (1)       (2)       (3)       (4)       FPRPT_C2         3. Difficulty remembering what he/she just heard       (0)       (1)       (2)       (3)       (4)       FPRPT_C3         4. Difficulty thinking quickly       (0)       (1)       (2)       (3)       (4)       FPRPT_C4         5. Trouble remembering what he/she was just thinking       (0)       (1)       (2)       (3)       (4)       FPRPT_C5         6. Trouble remembering more than one       (0)       (1)       (2)       (3)       (4)       FPRPT_C5		3.	Feeling tired when he/she wakes up in						
5. Taking a lot of naps (0) (1) (2) (3) (4) FPRPT_B5 6. Spending a lot of time in bed (0) (1) (2) (3) (4) FPRPT_B6  C. Cognitive fatigue (problems with)  1. Difficulty keeping his/her attention on things (0) (1) (2) (3) (4) FPRPT_C1  2. Difficulty remembering what people tell him/her (0) (1) (2) (3) (4) FPRPT_C2  3. Difficulty remembering what he/she just heard (0) (1) (2) (3) (4) FPRPT_C3  4. Difficulty thinking quickly (0) (1) (2) (3) (4) FPRPT_C4  5. Trouble remembering what he/she was just thinking (0) (1) (2) (3) (4) FPRPT_C5  6. Trouble remembering more than one			the morning	(0)	(1)	(2)	(3)	(4)	FPRPT_B3
6. Spending a lot of time in bed  (0) (1) (2) (3) (4)  FPRPT_B6  C. Cognitive fatigue (problems with)  1. Difficulty keeping his/her attention on things (0) (1) (2) (3) (4)  FPRPT_C1  2. Difficulty remembering what people tell him/her (0) (1) (2) (3) (4)  FPRPT_C2  3. Difficulty remembering what he/she just heard (0) (1) (2) (3) (4)  FPRPT_C3  4. Difficulty thinking quickly (0) (1) (2) (3) (4)  FPRPT_C3  FPRPT_C4  5. Trouble remembering what he/she was just thinking (0) (1) (2) (3) (4)  FPRPT_C5  FPRPT_C5		4.		(0)	(1)	(2)	(3)	(4)	FPRPT_B4
C. Cognitive fatigue (problems with)  1. Difficulty keeping his/her attention on things  2. Difficulty remembering what people tell him/her  3. Difficulty remembering what he/she just heard  4. Difficulty thinking quickly  5. Trouble remembering what he/she was just thinking  (0) (1) (2) (3) (4) FPRPT_C3  FPRPT_C3  FPRPT_C4  FPRPT_C5  (0) (1) (2) (3) (4) FPRPT_C4  FPRPT_C5  FPRPT_C5  FPRPT_C5		5.	Taking a lot of naps	(0)	(1)	(2)	(3)	(4)	FPRPT_B5
1. Difficulty keeping his/her attention on things (0) (1) (2) (3) (4) FPRPT_C1  2. Difficulty remembering what people tell him/her (0) (1) (2) (3) (4) FPRPT_C2  3. Difficulty remembering what he/she just heard (0) (1) (2) (3) (4) FPRPT_C3  4. Difficulty thinking quickly (0) (1) (2) (3) (4) FPRPT_C4  5. Trouble remembering what he/she was just thinking (0) (1) (2) (3) (4) FPRPT_C5  6. Trouble remembering more than one		6.	Spending a lot of time in bed	(0)	(1)	(2)	(3)	(4)	FPRPT_B6
1. Difficulty keeping his/her attention on things (0) (1) (2) (3) (4) FPRPT_C1  2. Difficulty remembering what people tell him/her (0) (1) (2) (3) (4) FPRPT_C2  3. Difficulty remembering what he/she just heard (0) (1) (2) (3) (4) FPRPT_C3  4. Difficulty thinking quickly (0) (1) (2) (3) (4) FPRPT_C4  5. Trouble remembering what he/she was just thinking (0) (1) (2) (3) (4) FPRPT_C5  6. Trouble remembering more than one									_
things (0) (1) (2) (3) (4) FPRPT_C1  2. Difficulty remembering what people tell him/her (0) (1) (2) (3) (4) FPRPT_C2  3. Difficulty remembering what he/she just heard (0) (1) (2) (3) (4) FPRPT_C3  4. Difficulty thinking quickly (0) (1) (2) (3) (4) FPRPT_C4  5. Trouble remembering what he/she was just thinking (0) (1) (2) (3) (4) FPRPT_C5  6. Trouble remembering more than one	C.	Cog	gnitive fatigue (problems with)						
2. Difficulty remembering what people tell him/her (0) (1) (2) (3) (4) FPRPT_C2  3. Difficulty remembering what he/she just heard (0) (1) (2) (3) (4) FPRPT_C3  4. Difficulty thinking quickly (0) (1) (2) (3) (4) FPRPT_C4  5. Trouble remembering what he/she was just thinking (0) (1) (2) (3) (4) FPRPT_C5  6. Trouble remembering more than one		1.	Difficulty keeping his/her attention on						
tell him/her (0) (1) (2) (3) (4) FPRPT_C2  3. Difficulty remembering what he/she just heard (0) (1) (2) (3) (4) FPRPT_C3  4. Difficulty thinking quickly (0) (1) (2) (3) (4) FPRPT_C4  5. Trouble remembering what he/she was just thinking (0) (1) (2) (3) (4) FPRPT_C5  6. Trouble remembering more than one			things	(0)	(1)	(2)	(3)	(4)	FPRPT_C1
3. Difficulty remembering what he/she just heard (0) (1) (2) (3) (4) FPRPT_C3  4. Difficulty thinking quickly (0) (1) (2) (3) (4)  5. Trouble remembering what he/she was just thinking (0) (1) (2) (3) (4)  6. Trouble remembering more than one		2.	Difficulty remembering what people						
just heard (0) (1) (2) (3) (4) FPRPT_C3  4. Difficulty thinking quickly (0) (1) (2) (3) (4)  5. Trouble remembering what he/she was just thinking (0) (1) (2) (3) (4)  6. Trouble remembering more than one				(0)	(1)	(2)	(3)	(4)	FPRPT_C2
4. Difficulty thinking quickly (0) (1) (2) (3) (4)  5. Trouble remembering what he/she was just thinking (0) (1) (2) (3) (4)  6. Trouble remembering more than one		3.							
5. Trouble remembering what he/she was just thinking (0) (1) (2) (3) (4) FPRPT_C5  6. Trouble remembering more than one						(2)	(3)		FPRPT_C3
was just thinking (0) (1) (2) (3) (4) FPRPT_C5  6. Trouble remembering more than one				(0)	(1)	(2)	(3)	(4)	FPRPT_C4
6. Trouble remembering more than one		5.							
				(0)	(1)	(2)	(3)	(4)	FPRPT_C5
thing at a time   (0)   (1)   (2)   (3)   (4)   FPRPT_C6		6.							
			thing at a time	(0)	(1)	(2)	(3)	(4)	FPRPT_C6

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### PART V: SICKLE CELL SCALES

### 1. **Child** Report (Ages 8-12)

In the past one month, how much of a problem has this been for you ...

			Never	Almost Never	Some- times	Often	Almost Always	
Α.	Abo	out my pain and hurt (problems with)		110101			ranayo	
	1.	I hurt a lot	(0)	(1)	(2)	(3)	(4)	SCRPT_A1
	2.	I hurt all over my body	(0)	(1)	(2)	(3)	(4)	SCRPT_A2
	3.	I hurt in my arms	(0)	(1)	(2)	(3)	(4)	SCRPT_A3
	4.	I hurt in my legs	(0)	(1)	(2)	(3)	(4)	SCRPT_A4
	5.	I hurt in my stomach	(0)	(1)	(2)	(3)	(4)	SCRPT_A5
	6.	I hurt in my chest	(0)	(1)	(2)	(3)	(4)	SCRPT_A6
	7.	I hurt in my back	(0)	(1)	(2)	(3)	(4)	SCRPT_A7
	8.	I have pain every day	(0)	(1)	(2)	(3)	(4)	SCRPT_A8
	9.	I have pain so much that I need		, ,	, ,	, ,	, ,	_
		medicine	(0)	(1)	(2)	(3)	(4)	SCRPT_A9
B.	Abo	out my pain impact (problems with)						
	1.	It is hard for me to do things because						
		I might get pain	(0)	(1)	(2)	(3)	(4)	SCRPT_B1
	2.	I miss school when I have pain	(0)	(1)	(2) (2)	(3)	(4)	SCRPT_B2
	3.	It is hard for me to run when I have						
		pain	(0)	(1)	(2)	(3)	(4)	SCRPT_B3
	4.	It is hard to have fun when I have						
		pain	(0)	(1)	(2)	(3)	(4)	SCRPT_B4
	5.	I have trouble moving when I have						
		pain	(0)	(1)	(2)	(3)	(4)	SCRPT_B5
	6.	It is hard to stay standing when I						
		have pain	(0)	(1)	(2)	(3)	(4)	SCRPT_B6
	7.	It is hard for me to take care of						
		myself when I have pain	(0)	(1)	(2)	(3)	(4)	SCRPT_B7
	8.	It is hard for me to do what others				4-1		
		can do because I might get pain	(0)	(1)	(2)	(3)	(4)	SCRPT_B8
	9.	I wake up at night when I have pain	(0)	(1)	(2)	(3)	(4)	SCRPT_B9
	10.	I get tired when I have pain	(0)	(1)	(2)	(3)	(4)	SCRPT_B10
				T		1	1	٦
C.		out my pain management and control oblems with)						
	1.	It is hard for me to manage my pain	(0)	(1)	(2)	(3)	(4)	SCRPT_C1
	2.	It is hard for me to control my pain	(0)	(1)	(2)	(3)	(4)	SCRPT_C1
		it to hard for the to control my pain	. (~)	\'/	\-/	(_)	1 ('/	

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In the past one month, how much of a problem has this been for you  $\dots$ 

			Never	Almost Never	Some- times	Ofte n	Almost Always	
D.	Abo	out my worrying I (problems with)		110101	unioo		ranayo	-
	1.	I worry that I will have pain	(0)	(1)	(2)	(3)	(4)	SCRPT_D1
	2.	I worry that others will not know what	` '	` ′				_
		to do if I have pain	(0)	(1)	(2)	(3)	(4)	SCRPT_D2
	3.	I worry when I am away from home	(0)	(1)	(2)	(3)	(4)	SCRPT_D3
	4.	I worry I might have to go to the						
		emergency room	(0)	(1)	(2)	(3)	(4)	SCRPT_D4
	5.	I worry I might have to stay overnight						
		in the hospital	(0)	(1)	(2)	(3)	(4)	SCRPT_D5
				T		ı	1	1
E.		About my worrying II (problems with)		(4)	(0)	(0)	(4)	-
	1.	I worry I might have a stroke	(0)	(1)	(2)	(3)	(4)	SCRPT_E1
	2.	I worry I might have a chest crisis	(0)	(1)	(2)	(3)	(4)	SCRPT_E2
	ΑΙ					I	1	1
F.		bout my emotions (problems with)		(4)	(0)	(0)	(4)	
	1.	I feel mad I have sickle cell disease	(0)	(1)	(2)	(3)	(4)	SCRPT_F1
	2.	I feel mad when I have pain	(0)	(1)	(2)	(3)	(4)	SCRPT_F2
G.	۸ha	out my treatment (problems with)				<u> </u>	1	1
G.	1.	It is hard for me to remember to take						
	١.	my medicine	(0)	(1)	(2)	(3)	(4)	SCRPT_G1
	2.	I do not like how I feel after I take my	(0)	(1)	(2)	(3)	(7)	SCRPI_GT
	۷.	medicine	(0)	(1)	(2)	(3)	(4)	SCRPT_G2
	3.	I do not like the way my medicine	(0)	(1)	(=)	(0)	(1)	30Ki 1_02
	0.	tastes	(0)	(1)	(2)	(3)	(4)	SCRPT_G3
	4.	My medicine makes me sleepy	(0)	(1)	(2)	(3)	(4)	SCRPT_G4
	5.	I worry about whether my medicine is	(-)			(-)		
		working	(0)	(1)	(2)	(3)	(4)	SCRPT_G5
	6.	I worry about whether my treatments		. ,	. ,	,	, ,	_
		are working	(0)	(1)	(2)	(3)	(4)	SCRPT_G6
	7.	My medicine does not make me feel						
		better	(0)	(1)	(2)	(3)	(4)	SCRPT_G7
								7
Н.	\1							
	1.	<ol> <li>It is hard for me to tell others when I am in pain</li> <li>It is hard for me to tell the doctors and</li> </ol>						
				(1)	(2)	(3)	(4)	SCRPT_H1
	2.				4-5			
-		nurses how I feel	(0)	(1)	(2)	(3)	(4)	SCRPT_H2
	3.	It is hard for me to ask the doctors	(6)	(4)	(6)	(6)	(4)	
		and nurses questions	(0)	(1)	(2)	(3)	(4)	SCRPT_H3

ID Number		_	Visit			Seq						
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			Never	Almost	Some-	Often	Almost	
				Never	times		Always	
Ι.	Abo	out communication II (problems with)						
	1.	It is hard for me when others do not						
		understand about my sickle cell disease	(0)	(1)	(2)	(3)	(4)	SCRPT_I1
	2.	It is hard for me when others do not						
		understand how much pain I feel	(0)	(1)	(2)	(3)	(4)	SCRPT_I2
	3.	It is hard for me to tell others I have						
		sickle cell disease	(0)	(1)	(2)	(3)	(4)	SCRPT_I3

# 2. **Parent** Report (Ages 8-12)

In the past one month, how much of a problem has your child had with ...

			Never	Almost Never	Some- times	Often	Almost Always	
Α.	Pair	n and hurt (problems with)		INCVCI	unics		Aiways	_
7	1.	Hurting a lot	(0)	(1)	(2)	(3)	(4)	SPRPT_A1
	2.	Hurting all over his/her body	(0)	(1)	(2)	(3)	(4)	SPRPT_A2
	3.	Hurting in his/her arms	(0)	(1)	(2)	(3)	(4)	SPRPT_A3
	4.	Hurting in his/her legs	(0)	(1)	(2)	(3)	(4)	SPRPT_A4
	5.	Hurting in his/her stomach	(0)	(1)	(2)	(3)	(4)	SPRPT_A5
	6.	Hurting in his/her chest	(0)	(1)	(2)	(3)	(4)	SPRPT_A6
	7.	Hurting in his/her back	(0)	(1)	(2)	(3)	(4)	SPRPT_A7
	8.	Having pain every day	(0)	(1)	(2)	(3)	(4)	SPRPT_A8
	9.	Having so much pain that he/she has			, ,	` '	, ,	_
		to take medicine	(0)	(1)	(2)	(3)	(4)	SPRPT_A9
								<u> </u>
B.	Pair	n impact (problems with)						
	1.	It is hard for him/her to do things						
		because he/she might get pain	(0)	(1)	(2)	(3)	(4)	SPRPT_B1
	2.	Missing school when he/she has pain	(0)	(1)	(2)	(3)	(4)	SPRPT_B2
	3.	It is hard for him/her to run when						
		he/she has pain	(0)	(1)	(2)	(3)	(4)	SPRPT_B3
	4.	It is hard for him/her to have fun						
		when having pain	(0)	(1)	(2)	(3)	(4)	SPRPT_B4
	5.	Having trouble moving around when						
	_	he/she has pain	(0)	(1)	(2)	(3)	(4)	SPRPT_B5
	6.	It is hard for him/her to stay standing	(2)		(5)	(=)		
		when he/she has pain	(0)	(1)	(2)	(3)	(4)	SPRPT_B6
	7.	It is hard for him/her to take care of	(0)	(4)	(0)	(0)	(4)	
		himself/herself when he/she has pain	(0)	(1)	(2)	(3)	(4)	SPRPT_B7
	8.	It is hard for him/her to do what						
		others can do because he/she might	(0)	(4)	(2)	(2)	(4)	
	0	get pain		(1)	(2)	(3)	(4)	SPRPT_B8
	9.	Waking up at night when he/she has pain	(0)	(1)	(2)	(2)	(4)	
	10	10. Getting tired when he/she has pain		(1)	(2)	(3)	(4)	SPRPT_B9
	10.		(0)	<u> </u>		(3)		SPRPT_B10
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In the past one month, how much of a problem has your child had with  $\dots$ 

			Never	Almost Never	Some- times	Often	Almost Always	
C.	Pai	n management and control (problems wi	th)					
	1.	It is hard for him/her to manage						
		his/her pain	(0)	(1)	(2)	(3)	(4)	SPRPT_C1
	2.	It is hard for him/her to control his/her						
		pain	(0)	(1)	(2)	(3)	(4)	SPRPT_C2
							T	-
D.		Worry I (problems with)						
	1.	Worrying that he/she will have pain	(0)	(1)	(2)	(3)	(4)	SPRPT_D1
	2.	Worrying that other people will not						
		know what to do if he/she has pain	(0)	(1)	(2)	(3)	(4)	SPRPT_D2
	3.	Worrying when he/she is away from						
		home	(0)	(1)	(2)	(3)	(4)	SPRPT_D3
	4.	Worrying he/she might have to go to						
		the emergency room	(0)	(1)	(2)	(3)	(4)	SPRPT_D4
	5.	Worrying he/she might have to stay						
		overnight in the hospital	(0)	(1)	(2)	(3)	(4)	SPRPT_D5
			Т	1		1	Γ	7
E.		rry II (problems with)						
	1.	Worrying he/she might have a stroke	(0)	(1)	(2)	(3)	(4)	SPRPT_E1
	2.	Worrying he/she might have a chest						
		crisis	(0)	(1)	(2)	(3)	(4)	SPRPT_E2
			Т	ı		1	Т	٦
F.		otions (problems with)						
	1.	Feeling mad about having sickle cell						
		disease	(0)	(1)	(2)	(3)	(4)	SPRPT_F1
	2.	Feeling mad when he/she has pain	(0)	(1)	(2)	(3)	(4)	SPRPT_F2
			Т	1		1	Γ	7
G.		atment (problems with)						
	1.	It is hard for him/her to remember to						
		take his/her medicine	(0)	(1)	(2)	(3)	(4)	SPRPT_G1
	2.	Not liking how he/she feels after						
		taking medicine	(0)	(1)	(2)	(3)	(4)	SPRPT_G2
	3.	Not liking the way his/her medicine						
		tastes	(0)	(1)	(2) (2)	(3)	(4)	SPRPT_G3
	4.	Medicine making him/her sleepy	(0)	(1)	(2)	(3)	(4)	SPRPT_G4
	5.	medicine is working  6. Worrying about whether his/her			(5)	(5)		
	L_			(1)	(2)	(3)	(4)	SPRPT_G5
	6.				(5)	(5)		
	<u> </u>	treatments are working	(0)	(1)	(2)	(3)	(4)	SPRPT_G6
	7.	Medicine not making him/her feel	(5)		(5)	(5)		
		better	(0)	(1)	(2)	(3)	(4)	SPRPT_G7

ID Number			Visit				Seq			
						-				

CERT\_NO

In the past one month, how much of a problem has your child had with ...

			Never	Almost Never	Some- times	Often	Almost Always	
Н.	Co	mmunication I (problems with)					,	
	1.	It is hard for him/her to tell others						
		when he/she is in pain	(0)	(1)	(2)	(3)	(4)	SPRPT_H1
	2.	It is hard for him/her to tell the doctors						
		and nurses how he/she feels	(0)	(1)	(2)	(3)	(4)	SPRPT_H2
	3.	It is hard for him/her to ask the						
		doctors and nurses questions	(0)	(1)	(2)	(3)	(4)	SPRPT_H3
I.	Co	mmunication II (problems with)						
	1.	It is hard for him/her when other						
		people do not understand about						
		his/her sickle cell disease	(0)	(1)	(2)	(3)	(4)	SPRPT_I1
	2.	It is hard for him/her when others do						
		not understand how much pain he/she						
		feels		(1)	(2)	(3)	(4)	SPRPT_I2
	3.							
		he/she has sickle cell disease	(0)	(1)	(2)	(3)	(4)	SPRPT_I3

#### **PART VI: COORDINATION**

1.

1.	Checked for completeness and accuracy:

A.	Certification number:	<u> </u>	CERT_NO
В.	Signature:		CERT_SIG
C.	General Comments:		GEN_CMNT

ID Number			Visit			Seq				
							-			