Intermittent Exotropia Questionnaire (IXTO)

(May 2008 version)

CHILD 5-7

Instructions for interviewer

I am going to ask you some questions about some things that might be a problem for some children. I would like to know how much of a problem any of these things might be for you.

If something is <u>not at all</u> a problem for you, point to the smiling face $\sqrt{2}$	9
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If something is <u>sometimes</u> a problem for you, point to the middle face

If something is a problem for you a lot, point to the sad face

I am going to read each question and then you can point to the picture to show me how much of a problem it is for you.

Let's try a practice question:

Is it hard for you to ride a bike?

Not at all	Sometimes	A lot
Ð	6	3

Instructions for clinician / researcher

The Intermittent Exotropia Questionnaire (IXTQ) has been developed to assess the impact of intermittent exotropia (IXT) on both the child with IXT and the parent of the child with IXT. The IXTQ is comprised of 3 parts:

- Child questionnaire: Assesses the impact of IXT on health related quality of life (HRQOL) of children ages 5 to 17 years. There are separate questionnaires for children aged 5 to 7 years and children aged 8 to 17 years.
- Proxy questionnaire: Assesses the impact of IXT on HRQOL of children ages 2 to 17 years with IXT.
- Parent questionnaire: Assesses the impact of DXT on HRQOL of the parent or legal guardian of children with DXT.

The IXTQ may be used in regular clinical practice or as a research tool. The IXTQ is intended to be completed by the child and the parent in a supervised clinical setting.

Please use the DXTQ along with the DXTQ instructions for each of the 3 questionnaires.

- Clinicians should review the *IXTQ Instructions for Interviewers* for the Child questionnaire. If possible, children should be positioned such that they are unable view their parents during testing and parents should be advised not to influence their child's responses. Children (5-7 years old) should be allowed to use the accompanying matching card.
- Parents or legal guardians should review DXTQ Instructions for Parents or Legal Guardians
 of the corresponding questionnaires prior to completing the Proxy and Parent questionnaires.

The DXTQ is available without charge and may be used in its unaltered entirety without restriction. If used for research, the questionnaire must be identified in all pertinent publications by name and by citing the original manuscript in *Ophthalmology* (Hatt SR, Leske DA, Yamada T, Bradley EA, Cole SR, Holmes JM. Development and initial validation of quality of life questionnaires for intermittent exotropia. *Ophthalmology* 2009 (in press)).

Scoring the IXTQ

Child Questionnaire

For each of the 12 Child questionnaire items, responses are scored as follows:

Child questionnaire for children ages 5 to 7 years

Response	Score
Not at all	100
Sometimes	50
A lot	0

Child questionnaire for children ages 8 to 17 years

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Response	Score
Never	100
Almost never	75
Sometimes	50
Often	25
Almost Always	0

Intermittent Exotropia Questionnaire (IXTQ)

Child Score

- The overall IXTQ Child score is calculated as the mean of all 12 item scores.
- If an item is unanswered, the overall score is calculated as the mean of all the answered items.
- Maximum possible overall score is 100 (best HRQOL) and minimum is 0 (worst HRQOL).

Proxy Questionnaire

For each of the 12 Proxy questionnaire items, responses are scored as follows:

Response	Score
Never	100
Almost never	75
Sometimes	50
Often	25
Almost Always	0

Proxy Score

- The overall IXTQ Proxy score is calculated as the mean of all 12 item scores.
- If an item is unanswered, the overall score is calculated as the mean of all the answared items.
- Maximum possible overall score is 100 (best HRQOL) and minimum is 0 (worst HRQOL).

Parent Questionnaire

For each of the 17 Parent questionnaire items, responses are scored as follows:

Response	Score
Never	100
Almost never	75
Sometimes	50
Often	25
Almost Always	0

Overall Parent Score

- The overall DXTQ Parent score is calculated as the mean of all 17 item scores.
- If an item is unanswered, the overall score is calculated as the mean of all the answared items.
- Maximum possible overall score is 100 (best HRQOL) and minimum is 0 (worst HRQOL).

Intermittent Exotropia Questionnaire (IXTQ)

Function Subscale

- The function subscale of the DXTQ Parent questionnaire is calculated as the mean of items 1-4, 6, 9, and 14-15.
- If an item is unanswered, the overall score is calculated as the mean of all the answared items.
- Maximum possible function score is 100 (best HRQOL) and minimum is 0 (worst HRQOL).

Psychosocial Subscale

- The psychosocial subscale of the IXTQ Parent questionnaire is calculated as the mean of items 5, 8, 10-13, and 17.
- If an item is unanswered, the overall score is calculated as the mean of all the answared items.
- Maximum possible psychosocial score is 100 (best HRQOL) and minimum is 0 (worst HRQOL).

Surgery Subscale

- The surgery subscale of the IXTQ Parent questionnaire is calculated as the mean of items 7 and 16
- If an item is unanswered, the overall score is calculated as the mean of all the answered items.
- Maximum possible surgery score is 100 (best HRQOL) and minimum is 0 (worst HRQOL).



Child's medical record #:

7) Does it bother you that you have to shut one eye when it is sunny?

Not at all	Sometimes	A Lot
(* *)	(* *)	.
<u> </u>	\bigcirc	\sim

8) Do you feel different from other kids because of your eyes?

Not at all	Sometimes	A Lot
(* *	(* *	R
<u> </u>	\sim	~

9) Are you worried what other people think of you because of your eyes?

Not at all	Sometimes	A Lot
(E)	(T)	E)
\sim	<u> </u>	~

10) Do you find it hard to look at people because of your eyes?

Not at all	Sometimes	A Lot
(1)	(*)	<u>e</u>

11) Is it hard for you to concentrate because of your eyes?

Not at all	Sometimes	A Lot
(P)	(* *)	A
<u> </u>	\bigcirc	\sim

12) Do your eyes make it hard to make friends?

Not at all	Sometimes	A Lot
	(* *)	R
	\sim	\sim

Intermittent Exotropia Questionnaire (IXTQ) (May 2008 version)

CHILD 8-17

Instructions

This questionnaire asks questions about how your eyes may affect you in your everyday life.

Instructions:

- On the next page is a list of things that might be a problem for you.
- Please tell us how much of a problem each one has been for you over the past month. There are no right or wrong answers.
- · Circle the answer that is closest to how you feel.
- · Circle only ONE answer for each statement.
- If you are not sure how to answer, please circle the answer you think is best.

If you do not understand a question or you are finding it difficult please ask for help.

Child's Name

Child's medical record #: _____

Date	1	1

I worry about my eyes

Never	Almost never	Sometimes	Often	Almost always		
2) It bothers me that people wonder what is wrong with my eyes						
Never	Almost never	Sometimes	Often	Almost always		
3) It bothers m	e because I have to a	wait for my eyes	to clear up			
Never	Almost never	Sometimes	Often	Almost always		
4) Kids tease m	e because of my eye	s				
Never	Almost never	Sometimes	Often	Almost always		
5) I am bothere	ed when grownups s		my eyes			
Never	Almost never	Sometimes	Often	Almost always		
6) I am bothere	d when my parents					
Never	Almost never	Sometimes	Often	Almost always		
7) It bothers me that I have to shut one eye when it is sunny						
Never	Almost never	Sometimes	Often	Almost always		
8) I feel different from other kids because my eyes go in and out						
Never	Almost never	Sometimes	Often	Almost always		
9) I worry about what other people think of me because of my eyes						
Never	Almost never	Sometimes	Often	Almost always		
10) My eyes ma	10) My eyes make it hard to look people in the eye					
Never	Almost never	Sometimes	Often	Almost always		
11) It is hard to	concentrate becaus	se of my eyes		-		
Never	Almost never	Sometimes	Often	Almost always		
120.14	les it hand for my to					

12) My eyes make it hard for me to make friends

Never Almost never Sometimes Often Almost always
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Intermittent Exotropia Questionnaire (IXTQ) (May 2008 version)

PROXY

Instructions for parent or legal guardian

The PROXY Intermittent Exotropia Questionnaire is a short questionnaire with statements about how you think your child's eye condition affects your child in their everyday life.

If you are unable to complete this on your own, please ask for someone to assist you.

Instructions:

- On the following page is a list of things that might be a problem for your child.
- Please respond to EACH statement by circling the response that best reflects how you think your child feels.
- Circle only ONE response for each statement.
- Please answer based on experiences during the past month.
- If you are not sure how to respond, please circle the response you think is most appropriate.

Intermittent Exotropia Questionnaire (IXTQ) PROXY

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-	ing questionnaire (a	circle one):	Mother	Father	Other legal guardian
Child's Name: Medical record #					
Medical record #			D	ate _ / _ /	
1) My child wor	rries about his/her e	eyes			_
Never	Almost never	Sometimes	Often	Almost always	
2) My child is b	othered about peop	le wondering	what is wrong wi	ith his/her eyes	
Never	Almost never	Sometimes	Often	Almost always	7
3) My child is b	othered because the	ey have to wai	t for his/her eyes	to clear up	-
Never	Almost never	Sometimes	Often	Almost always	
4) Kids tease m	y child because of h	is/her eyes			
Never	Almost never	Sometimes	Often	Almost always	
5) My child is b	othered when adult	s say things a	bout his/her eyes	i	_
Never	Almost never	Sometimes	Often	Almost always	
6) My child is b	othered when his/h	er parents say	things about his	/ber eyes	
Never	Almost never	Sometimes	Often	Almost always	
7) It bothers my	y child because he/s	he has to shut	one eye when it i	is sunny	
Never	Almost never	Sometimes	Often	Almost always	
8) My child feel	s different from oth	er kids becau	se of his/her eyes		_
Never	Almost never	Sometimes	Often	Almost always	
9) My child wor	rries about what oth	ier people this	ak of him/her bec	ause of his/her ey	e
Never	Almost never	Sometimes	Often	Almost always	
	ids it hard to look p				
Never	Almost never	Sometimes	Often	Almost always	
11) My child fir	ds it hard to conce	ntrate because	of his/her eyes		
Never	Almost never	Sometimes	Often	Almost always	
12) My child's e	eyes make it hard fo	r him/her to 1	nake friends		
Never	Almost never	Sometimes	Often	Almost always	
					_

Intermittent Exotropia Questionnaire (IXTQ) (May 2008 version)

PARENT

Instructions for parent or legal guardian

The PARENT Intermittent Exotropia Questionnaire is a short questionnaire with statements about how your child's eye condition may affect you in your everyday life.

If you are unable to complete this on your own, please ask for someone to assist you.

Instructions:

- On the following page is a list of things that might be a problem for you.
- Please respond to EACH statement by circling the response that best reflects how you feel.
- · Circle only ONE response for each statement.
- Please answer based on your experiences during the past month.
- If you are not sure how to respond, please circle the response you think is most appropriate.

		-			
Person complet	ing questionnaire (a	ircle one)	Mother	Father	Other legal guardian
Child's Name:		`			
Medical record #	ŧ			Date//	_
l) I worry abou	t my child's eyes				
Never	Almost never	Sometimes	Often	Almost always	
2) I worry that :	my child will be les:	independent	because of his/h	er eyes	
Never	Almost never	Sometimes	Often	Almost always	
3) I worry that :	my child will have p	ermanent da	mage to his/her e	eyes	_
Never	Almost never	Sometimes	Often	Almost always	
4) I worry that :	my child doesn't se	e well	•	•	_
Never	Almost never	Sometimes	Often	Almost always	
5) I worry abou	t how my child's ey	es will affect l	him/her socially		_
Never	Almost never	Sometimes	Often	Almost always	7
6) I worry that	my child will get hu	rt physically i	because of his/he	r eyes	
Never	Almost never	Sometimes	Often	Almost always	
7) I worry abou	t the possibility of s	urgery			
Never	Almost never	Sometimes	Often	Almost always	
8) I worry abou	t my child becomin	g self conscio	as because of his	/her eyes	
Never	Almost never	Sometimes	Often	Almost always]
9) I worry that :	my child will not be	able to see th	e board at schoo	d	
Never	Almost never	Sometimes	Often	Almost always	
10) I worry abo	ut other kids teasin	g my child be	cause of his/her (eyes	
Never	Almost never	Sometimes	Often	Almost always	7
11) It worries m	ue what others will (think about m	y child because (of his/her eyes	-

Never Almost never Sometimes Often Almost always

Medical record #: _____

12) I worry that my child's eye condition will affect his/her personality

Never	Almost never	Sometimes	Often	Almost always	
13) I worry that my child's eyes will affect his/her social life if nothing is done					
Never	Almost never	Sometimes	Often	Almost always	

14) I worry about my child's eyesight long term

Never Almost never Sometimes Often	Almost always

15) I worry about my child's depth perception

Never	Almost never	Sometimes	Often	Almost always

16) I worry about whether or not my child should have surgery

Never Almost never Sometimes Often Almost always
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17) I worry about my child's ability to make friends

Never Almost never Sometimes Often Almost alv	ways