

# Intermittent Exotropia Questionnaire (IXTQ)


(December 2014 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 not at all a problem for you, point to the smiling face 




If something is sometimes 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
		

Child's Name: \_\_\_\_\_




Child's medical record #: \_\_\_\_\_

Date \_\_\_/\_\_\_/\_\_\_




**1) Are you worried about your eyes?**

Not at all 	Sometimes 	A Lot 
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**2) Does it bother you that people ask what is wrong with your eyes?**

Not at all 	Sometimes 	A Lot 
---	--	--




**3) Does it bother you because you have to wait for your eyes to clear up?**

Not at all 	Sometimes 	A Lot 
---	--	--




**4) Do kids tease you because of your eyes?**

Not at all 	Sometimes 	A Lot 
---	--	--

**5) Does it bother you when grownups say things about your eyes?**




Not at all 	Sometimes 	A Lot 
---	--	--

**6) Does it bother you when your dad or mom say things about your eyes?**




Not at all 	Sometimes 	A Lot 
---	--	--

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 
---	--	--




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

Not at all 	Sometimes 	A Lot 
---	--	--




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

Not at all 	Sometimes 	A Lot 
---	--	--




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

Not at all 	Sometimes 	A Lot 
---	--	--

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

Not at all 	Sometimes 	A Lot 
---	--	--

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

Not at all 	Sometimes 	A Lot 
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**Intermittent Exotropia Questionnaire  
(IXTQ)**

(December 2014 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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Person completing questionnaire (*circle one*):

<b>Mother</b>	<b>Father</b>	<b>Other legal guardian</b>
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Child's Name: \_\_\_\_\_

Medical record #: \_\_\_\_\_

Date \_\_\_/\_\_\_/\_\_\_

**1) My child worries about his/her eyes**

Never	Almost never	Sometimes	Often	Almost always
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**2) My child is bothered about people wondering what is wrong with his/her eyes**

Never	Almost never	Sometimes	Often	Almost always
-------	--------------	-----------	-------	---------------

**3) My child is bothered because they have to wait for their eyes to clear up**

Never	Almost never	Sometimes	Often	Almost always
-------	--------------	-----------	-------	---------------

**4) Kids tease my child because of his/her eyes**

Never	Almost never	Sometimes	Often	Almost always
-------	--------------	-----------	-------	---------------

**5) My child is bothered when adults say things about his/her eyes**

Never	Almost never	Sometimes	Often	Almost always
-------	--------------	-----------	-------	---------------

**6) My child is bothered when his/her parents say things about his/her eyes**

Never	Almost never	Sometimes	Often	Almost always
-------	--------------	-----------	-------	---------------

**7) It bothers my child because he/she has to shut one eye when it is sunny**

Never	Almost never	Sometimes	Often	Almost always
-------	--------------	-----------	-------	---------------

**8) My child feels different from other kids because of his/her eyes**

Never	Almost never	Sometimes	Often	Almost always
-------	--------------	-----------	-------	---------------

**9) My child worries about what other people think of him/her because of his/her eyes**

Never	Almost never	Sometimes	Often	Almost always
-------	--------------	-----------	-------	---------------

**10) My child finds it hard to look people in the eye**

Never	Almost never	Sometimes	Often	Almost always
-------	--------------	-----------	-------	---------------

**11) My child finds it hard to concentrate because of his/her eyes**

Never	Almost never	Sometimes	Often	Almost always
-------	--------------	-----------	-------	---------------

**12) My child's eyes make it hard for him/her to make friends**

Never	Almost never	Sometimes	Often	Almost always
-------	--------------	-----------	-------	---------------

**Intermittent Exotropia Questionnaire  
(IXTQ)**

(December 2014 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 completing questionnaire (*circle one*)

<b>Mother</b>	<b>Father</b>	<b>Other legal guardian</b>
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Child's Name: \_\_\_\_\_

Medical record #: \_\_\_\_\_

Date \_\_\_/\_\_\_/\_\_\_

**1) I worry about my child's eyes**

Never	Almost never	Sometimes	Often	Almost always
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**2) I worry that my child will be less independent because of his/her eyes**

Never	Almost never	Sometimes	Often	Almost always
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**3) I worry that my child will have permanent damage to his/her eyes**

Never	Almost never	Sometimes	Often	Almost always
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**4) I worry that my child doesn't see well**

Never	Almost never	Sometimes	Often	Almost always
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**5) I worry about how my child's eyes will affect him/her socially**

Never	Almost never	Sometimes	Often	Almost always
-------	--------------	-----------	-------	---------------

**6) I worry that my child will get hurt physically because of his/her eyes**

Never	Almost never	Sometimes	Often	Almost always
-------	--------------	-----------	-------	---------------

**7) I worry about the possibility of surgery**

Never	Almost never	Sometimes	Often	Almost always
-------	--------------	-----------	-------	---------------

**8) I worry about my child becoming self-conscious because of his/her eyes**

Never	Almost never	Sometimes	Often	Almost always
-------	--------------	-----------	-------	---------------

**9) I worry that my child will not be able to see the board at school**

Never	Almost never	Sometimes	Often	Almost always
-------	--------------	-----------	-------	---------------

**10) I worry about other kids teasing my child because of his/her eyes**

Never	Almost never	Sometimes	Often	Almost always
-------	--------------	-----------	-------	---------------

**11) It worries me what others will think about my 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
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**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
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**15) I worry about my child's depth perception**

Never	Almost never	Sometimes	Often	Almost always
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**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 always
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# Intermittent Exotropia Questionnaire (IXTQ)

## **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:

- 1) 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.
- 2) Proxy questionnaire: Assesses the impact of IXT on HRQOL of children ages 2 to 17 years with IXT.
- 3) Parent questionnaire: Assesses the impact of IXT on HRQOL of the parent or legal guardian of children with IXT.

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 IXTQ along with the IXTQ 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 *IXTQ Instructions for Parents or Legal Guardians* of the corresponding questionnaires prior to completing the Proxy and Parent questionnaires.

The IXTQ 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* 2010;117(1):163-168).

## **Scoring the IXTQ**

It is recommended that the IXTQ be scored using the Rasch IXTQ look-up tables available at <http://pedig.jaeb.org/ViewPage.aspx?PageName=Reference>. The tables may be downloaded and used as an automated way to provide Rasch-calibrated scores (Leske DA, Holmes JM, and Melia BM. Evaluation of the Intermittent Exotropia Questionnaire using Rasch analysis. *JAMA Ophthalmol* 2015 in press). Alternatively, the IXTQ may be scored using non-Rasch methods as outlined below:

# Intermittent Exotropia Questionnaire (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

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

### *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 *answered* items.
- Maximum possible overall score is 100 (best HRQOL) and minimum is 0 (worst HRQOL).

# Intermittent Exotropia Questionnaire (IXTQ)

## **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 IXTQ 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 *answered* items.
- Maximum possible overall score is 100 (best HRQOL) and minimum is 0 (worst HRQOL).

### *Function Subscale*

- The function subscale of the IXTQ 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 *answered* items.
- Maximum possible function score is 100 (best HRQOL) and minimum is 0 (worst HRQOL).

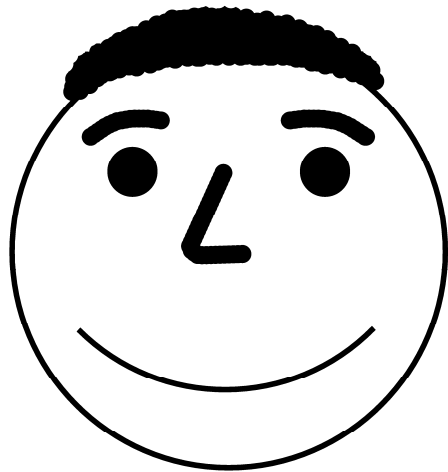
### *Psychosocial Subscale*

- 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 *answered* items.
- Maximum possible psychosocial score is 100 (best HRQOL) and minimum is 0 (worst HRQOL).

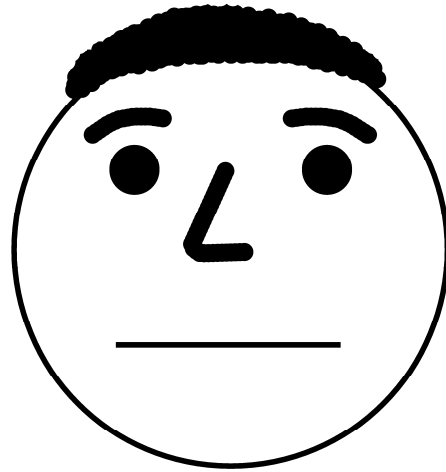
### *Surgery Subscale*

- 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).

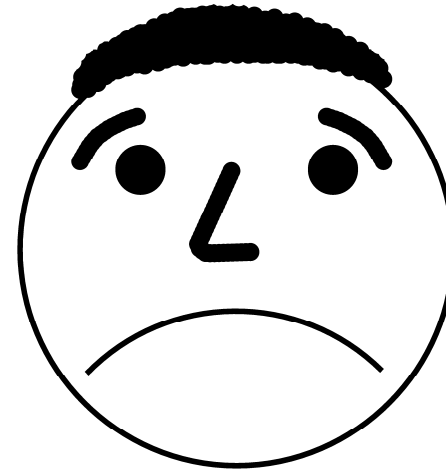
Intermittent Exotropia Questionnaire (IXTQ)



Not at all



Sometimes



A lot