

YOUTH QUALITY OF LIFE INSTRUMENT

Youth Quality of Life Instrument – Facial Differences Module (YQOL-FD)

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COMPLETED BY INTERVIEWER - ADMINISTRATION MODE (CIRCLE THE NUMBER):

- 1 In-person - Self administered
- 2 In-person - Interviewer read items
- 3 In-person - Interviewer read items and marked responses
- 4 Mail - Self administered

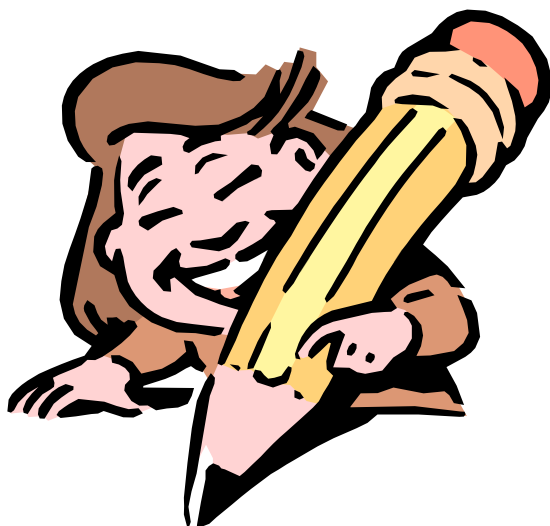
To all participants:

Many teens are taking part in this important survey. This survey will help us understand your thoughts and concerns so that better programs can be developed to improve the lives of teenagers with facial differences.

The questions in this survey ask about a wide range of concerns and feelings. Some of these may or may not be important to you.

This is NOT a test, there are no right or wrong answers. Please answer as honestly as you can. Your responses will be kept strictly secret.

Thank you for your help!



Describing How the Difference in Your Face Affects Your Life

Following are some statements that you might make about yourself. Please circle the one answer for each statement that best describes how closely the statement applies to you. There are no right or wrong answers, we are only interested in how you feel about your life.

- | | | | | | |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------|---------------------------------|---------------------------|---------------------------------|-------------------------------|
| 1. How often do you meet people with a facial difference like yours? <i>(please circle your answer)</i> | ⁰
NEVER | ¹
ALMOST
NEVER | ²
SOMETIMES | ³
FAIRLY
OFTEN | ⁴
VERY
OFTEN |
| 2. How often do you have your picture taken? <i>(please circle your answer)</i> | ⁰
NEVER | ¹
ALMOST
NEVER | ²
SOMETIMES | ³
FAIRLY
OFTEN | ⁴
VERY
OFTEN |
| 3. During the <i>past 7 days</i> , how often did you notice other people staring at your face? <i>(please circle your answer)</i> | ⁰
NEVER | ¹
ALMOST
NEVER | ²
SOMETIMES | ³
FAIRLY
OFTEN | ⁴
VERY
OFTEN |
| 4. During the <i>past 4 weeks</i> , how often did you talk with someone about how your face looks? <i>(please circle your answer)</i> | ⁰
NEVER | ¹
ALMOST
NEVER | ²
SOMETIMES | ³
FAIRLY
OFTEN | ⁴
VERY
OFTEN |
| 5. During the <i>past 4 weeks</i> , how often did you hear other people say something about how your face looks? <i>(please circle your answer)</i> | ⁰
NEVER | ¹
ALMOST
NEVER | ²
SOMETIMES | ³
FAIRLY
OFTEN | ⁴
VERY
OFTEN |
| 6. During the <i>past 4 weeks</i> , how often did you tell other people the same age as you about your facial difference? <i>(please circle your answer)</i> | ⁰
NEVER | ¹
ALMOST
NEVER | ²
SOMETIMES | ³
FAIRLY
OFTEN | ⁴
VERY
OFTEN |
| 7. During the <i>past 4 weeks</i> , how often were you left out from doing things that other people your age were doing because of how your face looks? <i>(please circle your answer)</i> | ⁰
NEVER | ¹
ALMOST
NEVER | ²
SOMETIMES | ³
FAIRLY
OFTEN | ⁴
VERY
OFTEN |
| 8. During the <i>past 4 weeks</i> , how often have you talked with someone you did not know? <i>(please circle your answer)</i> | ⁰
NEVER | ¹
ALMOST
NEVER | ²
SOMETIMES | ³
FAIRLY
OFTEN | ⁴
VERY
OFTEN |
| 9. During the <i>past 4 weeks</i> , how often have you walked around in public? <i>(please circle your answer)</i> | ⁰
NEVER | ¹
ALMOST
NEVER | ²
SOMETIMES | ³
FAIRLY
OFTEN | ⁴
VERY
OFTEN |
| 10. During the <i>past 4 weeks</i> , how often did you get into fights with your parents having to do with treatments for your face or head? <i>(please circle your answer)</i> | ⁰
NEVER | ¹
ALMOST
NEVER | ²
SOMETIMES | ³
FAIRLY
OFTEN | ⁴
VERY
OFTEN |

- | | | | | | |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------|---------------------------------|---------------------------|---------------------------------|-------------------------------|
| 11. During the <i>past 4 weeks</i> , how often were you invited to hang out with a new group of people? (<i>please circle your answer</i>) | ⁰
NEVER | ¹
ALMOST
NEVER | ²
SOMETIMES | ³
FAIRLY
OFTEN | ⁴
VERY
OFTEN |
| 12. During the <i>past 4 weeks</i> , how often did other people hug you? (<i>please circle your answer</i>) | ⁰
NEVER | ¹
ALMOST
NEVER | ²
SOMETIMES | ³
FAIRLY
OFTEN | ⁴
VERY
OFTEN |
| 13. During the <i>past 4 weeks</i> , how often have other people talked to you slowly or in a loud voice? (<i>please circle your answer</i>) | ⁰
NEVER | ¹
ALMOST
NEVER | ²
SOMETIMES | ³
FAIRLY
OFTEN | ⁴
VERY
OFTEN |
| 14. During the <i>past 4 weeks</i> , how often did you have to repeat what you said so that other people could understand you? (<i>please circle your answer</i>) | ⁰
NEVER | ¹
ALMOST
NEVER | ²
SOMETIMES | ³
FAIRLY
OFTEN | ⁴
VERY
OFTEN |
| 15. During the <i>past 4 weeks</i> , how often did you get into a fight with anyone because of how your face looks? (<i>please circle your answer</i>) | ⁰
NEVER | ¹
ALMOST
NEVER | ²
SOMETIMES | ³
FAIRLY
OFTEN | ⁴
VERY
OFTEN |
| 16. During the <i>past 4 weeks</i> , how often were you teased about how your face looks? (<i>please circle your answer</i>) | ⁰
NEVER | ¹
ALMOST
NEVER | ²
SOMETIMES | ³
FAIRLY
OFTEN | ⁴
VERY
OFTEN |
| 17. During the <i>past 6 months</i> , how often did you go out with a girlfriend or boyfriend? (<i>please circle your answer</i>) | ⁰
NEVER | ¹
ALMOST
NEVER | ²
SOMETIMES | ³
FAIRLY
OFTEN | ⁴
VERY
OFTEN |
| 18. During the <i>past 6 months</i> , how often did you get invited to parties? (<i>please circle your answer</i>) | ⁰
NEVER | ¹
ALMOST
NEVER | ²
SOMETIMES | ³
FAIRLY
OFTEN | ⁴
VERY
OFTEN |

Evaluating How the Difference in Your Face Affects Your Life

Following are some statements that you might make about your face, head, or mouth. For each statement please circle one number, 0 through 10, that best describes your feelings *daily*. There are no right or wrong answers; we are only interested in how you feel about your life. *Note: "Face" means face, head, or mouth.*

19. Because of how my face looks, I am in touch with other people's feelings (*please circle the number*)

NOT AT ALL		0	1	2	3	4	5	6	7	8	9	10		A GREAT DEAL
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20. People stare at me because of how my face looks (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL
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21. Because of how my face looks, I have more anger inside me than most people know (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL
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22. I have learned how to deal with people teasing me because of how my face looks (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL
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23. Because of how my face looks, I am more accepting of other people (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL
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24. I have gotten used to people making fun of how my face looks (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	COMPLETELY
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25. It makes me angry when grown-ups stare at me because of how my face looks (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL
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26. I have learned to live with people being curious about how my face looks (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	COMPLETELY
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27. I am a stronger person because of how my face looks (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL
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28. Because of how my face looks, people think I am stupid (*please circle the number*)

NOT AT ALL		0	1	2	3	4	5	6	7	8	9	10		A GREAT DEAL
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29. I feel uncomfortable meeting people for the first time because of how my face looks (*please circle the number*)

NOT AT ALL		0	1	2	3	4	5	6	7	8	9	10		A GREAT DEAL
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30. I feel self-conscious because of how my face looks (*please circle the number*)

NOT AT ALL		0	1	2	3	4	5	6	7	8	9	10		A GREAT DEAL
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31. Because of how my face looks, I feel I have no control over my life (*please circle the number*)

NOT AT ALL		0	1	2	3	4	5	6	7	8	9	10		A GREAT DEAL
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32. Because of how my face looks it is difficult to find friends I can trust (*please circle the number*)

NOT AT ALL		0	1	2	3	4	5	6	7	8	9	10		A GREAT DEAL
------------	--	---	---	---	---	---	---	---	---	---	---	----	--	--------------

33. I try not to pay attention to other people when they say things about my face (*please circle the number*)

NOT AT ALL		0	1	2	3	4	5	6	7	8	9	10		COMPLETELY
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34. Looking more like everyone else is important to me (*please circle the number*)

NOT AT ALL		0	1	2	3	4	5	6	7	8	9	10		A GREAT DEAL
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35. I feel frustrated about how my face looks (*please circle the number*)

NOT AT ALL		0	1	2	3	4	5	6	7	8	9	10		A GREAT DEAL
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36. Other people my age are embarrassed to be seen with me because of how my face looks (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL
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37. Because of how my face looks, I know more about life than other people my age do (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL
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38. Having a facial difference decreases my chances of success in life (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL
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39. Because of my facial difference, people judge me on how I look (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL
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40. Because of how my face looks, people have a hard time seeing who I really am (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL
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41. It is difficult to get a girlfriend or boyfriend because of how my face looks (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL
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42. Because of how my face looks, it is hard for me to walk around in public (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL
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43. Because of how my face looks, I need to prove myself to other people (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL
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44. I feel I get away with doing less than I could because of how my face looks (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	COMPLETELY
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45. I dislike looking at pictures of myself because of how my face looks (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL
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46. My facial difference has helped me to accept other people for who they are (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL
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47. I feel like I do not fit in with other people because of how my face looks (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL
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48. I avoid looking in the mirror because of my how my face looks (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL
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