

## User instructions for a questionnaire designed to measure quality of life among people with a stoma: The Stoma-QoL

The Stoma-QoL is developed to measure quality of life among people with a stoma. The questions in Stoma-QoL are outcomes of a lot of interviews with people with a stoma, which were carried out in several countries in order to address the issues that were most relevant in relation to quality of life for this group of people.

The following issues are covered: Concerns about sleeping, concerns about intimate relations, concerns regarding relationships with family and close friends and concerns regarding relationships with people other than family and close friends.

The questionnaire consists of 20 questions. An example of a question could be: "I worry that the pouch will loosen." All the questions must be answered on a 4-point scale. The options for answering each question are:

1. Always
2. Sometimes
3. Rarely
4. Not at all

Please be aware that **ALL** 20 questions must be answered in order for the questionnaire to work. Therefore, there should not be any unanswered questions. Furthermore, **ONLY ONE** answer must be given for each question.

The questions are very simple and it will take approximately 5-10 minutes to complete the questionnaire.

*Have a good time with the Stoma-QoL*

**Stoma-QOL**  
**A Quality of Life Questionnaire**  
**For People with Ostomy**

Date: \_\_\_\_/\_\_\_\_/20\_\_\_\_

*Please check the response that best describes how you are feeling **at the moment***

	Always	Sometimes	Rarely	Not-at-all
1. I become anxious when the pouch is full	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>	<input type="checkbox"/> <sup>3</sup>	<input type="checkbox"/> <sup>4</sup>
2. I worry that the pouch will loosen	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>	<input type="checkbox"/> <sup>3</sup>	<input type="checkbox"/> <sup>4</sup>
3. I feel the need to know where the nearest toilet is	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>	<input type="checkbox"/> <sup>3</sup>	<input type="checkbox"/> <sup>4</sup>
4. I worry that the pouch may smell	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>	<input type="checkbox"/> <sup>3</sup>	<input type="checkbox"/> <sup>4</sup>
5. I worry about noises from the stoma	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>	<input type="checkbox"/> <sup>3</sup>	<input type="checkbox"/> <sup>4</sup>
6. I need to rest during the day	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>	<input type="checkbox"/> <sup>3</sup>	<input type="checkbox"/> <sup>4</sup>
7. My stoma pouch limits the choice of clothes that I can wear	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>	<input type="checkbox"/> <sup>3</sup>	<input type="checkbox"/> <sup>4</sup>
8. I feel tired during the day	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>	<input type="checkbox"/> <sup>3</sup>	<input type="checkbox"/> <sup>4</sup>
9. My stoma makes me feel sexually unattractive	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>	<input type="checkbox"/> <sup>3</sup>	<input type="checkbox"/> <sup>4</sup>
10. I sleep badly during the night	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>	<input type="checkbox"/> <sup>3</sup>	<input type="checkbox"/> <sup>4</sup>
11. I worry that the pouch rustles	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>	<input type="checkbox"/> <sup>3</sup>	<input type="checkbox"/> <sup>4</sup>
12. I feel embarrassed about my body because of my stoma	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>	<input type="checkbox"/> <sup>3</sup>	<input type="checkbox"/> <sup>4</sup>
13. It would be difficult for me to stay away from home overnight	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>	<input type="checkbox"/> <sup>3</sup>	<input type="checkbox"/> <sup>4</sup>
14. It is difficult to hide the fact that I wear a pouch	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>	<input type="checkbox"/> <sup>3</sup>	<input type="checkbox"/> <sup>4</sup>
15. I worry that my condition is a burden to people close to me	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>	<input type="checkbox"/> <sup>3</sup>	<input type="checkbox"/> <sup>4</sup>
16. I avoid close physical contact with my friends	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>	<input type="checkbox"/> <sup>3</sup>	<input type="checkbox"/> <sup>4</sup>
17. My stoma makes it difficult for me to be with other people	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>	<input type="checkbox"/> <sup>3</sup>	<input type="checkbox"/> <sup>4</sup>
18. I am afraid of meeting new people	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>	<input type="checkbox"/> <sup>3</sup>	<input type="checkbox"/> <sup>4</sup>
19. I feel lonely even when I am with other people	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>	<input type="checkbox"/> <sup>3</sup>	<input type="checkbox"/> <sup>4</sup>
20. I worry that my family feels awkward around me	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>	<input type="checkbox"/> <sup>3</sup>	<input type="checkbox"/> <sup>4</sup>

*Please answer all questions. Thank you for filling out the questionnaire.*