

Appendix A: First version of the SWAMECO questionnaire in English

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University College Cork, Ireland
Coláiste na hOiscoilte Corcaigh

Pharmaceutical Care Research Group
Cavanagh Pharmacy Building
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Questionnaire on swallowing difficulties with medication intake

Dear participant

This questionnaire was developed to find out and to understand how people with swallowing difficulties deal with taking medicines. Our aim is that by using these results we will be able to recognise patients with swallowing difficulties at an earlier stage and therefore improve patient safety and quality of life. Swallowing difficulties affect people in different ways. Due to this, there are no right or wrong answers. All the answers and details you give will be anonymised so that there is no chance any of the details can be attributed to you.

The questionnaire has 41 questions over four pages and will take approximately 15 minutes to complete. Most of the questions are phrased so that you choose your answer by putting an "X" in the box. Unless the question mentions a different way of answering it, we would be grateful if you could answer just by using the "X" in the relevant box.

Once you have completed the questionnaire, please return it to the researcher or alternatively return it in the stamped addressed envelope provided to the study team at University College Cork.

Thank you so much for participating!

Personal details

ID:	Year of Birth:	Sex:	<input type="checkbox"/> Female
			<input type="checkbox"/> Male

		Yes	No
1	Currently, do you take at least one medicine that you have to swallow?	<input type="checkbox"/>	<input type="checkbox"/>

Do you experience swallowing difficulties...		Yes, currently	Yes, in the past	No, never
2	... when you drink?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	... when you eat?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	... when you take your medicines?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you have answered "Yes" to any of the questions 2,3 or 4, then please go to Question 5 on page 2.
If you have answered "No" to all of the questions 2,3 and 4 then please go to Question 10 on page 3.

SWAMECO_patient self-report_EN_V2.2

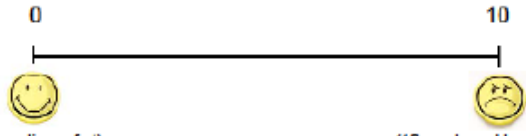
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Please read the following statements and put an "X" in the box which represents your view most closely:

		Strongly agree	Agree	Disagree	Strongly disagree	Not applicable
5	Swallowing medicines used to, or still causes me, to feel like I am....					
5.1	... choking.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.2	... having a fit of coughing.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.3	... going to gag or be sick.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.4	... having difficulty breathing like a tightness in the chest.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	During the day I have a dry mouth.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	Often I have to have a sip of water to help me to speak.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	I have an unpleasant burning sensation in my mouth.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	Both my eyes and my nostrils feel dry.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10	I have the feeling that my medicines get stuck in my throat.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11	Swallowing medicines causes pain.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12	In the last four weeks I have been worried about my swallowing difficulties.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13	Sometimes I will purposely not take a medicine because taking it will cause me swallowing difficulties.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14	As a result of my swallowing difficulties I am afraid of the next time I have to take my medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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15 Think of a time, either now or in the past, that you had to take a medicine which caused you discomfort or difficulties. Mark on the line below with a dash or an "X" between 0 and 10, how much discomfort you felt.

0 10

 (0 = no discomfort) (10 = unbearable discomfort)

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16 In the diagram below, please mark with an "X" where you have had, or still have, swallowing difficulties when you take your medicines.

Describe how this feels
(e.g. the capsule gets stuck, pain, need to cough)

(There may be more than one "X" and more than one answer to this question)

17 Which of your medicine(s) caused these swallowing difficulties?
(please give details of the name and the dose e.g. Nuseals Aspirin 75mg, 1 to be taken daily)

		Head tilted slightly forward	Head straight	Head tilted slightly back
18	How would you describe the position of your head as you swallow your medicines?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

		Yes	No	Not applicable
19	Have you ever modified your medicine in any way, shape or form, to make it easier to take?	<input type="checkbox"/> Please go to Question 20	<input type="checkbox"/> Please go to Question 22	<input type="checkbox"/> Please go to Question 22

20 Please describe how the medicine is modified (more than one answer is possible):

Splitting tablets Opening capsules Chewing tablets

Crushing tablets Dispersing tablets in a liquid

Other please describe: _____

Please describe what you do using key words / short notes

		Yes	No	Not applicable
21	Did you ask your doctor or pharmacist for advice before you modified your medicine(s)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

		Yes	No
22	Has your doctor ever asked you about swallowing difficulties?	<input type="checkbox"/>	<input type="checkbox"/>
23	Has your pharmacist ever asked you about swallowing difficulties?	<input type="checkbox"/>	<input type="checkbox"/>
24	Has your doctor or pharmacist ever offered you a different formulation (syrup, liquid, smaller tablets) instead of the tablets or capsules you receive?	<input type="checkbox"/>	<input type="checkbox"/>
25	Do you eat something (e.g. yoghurt) whilst taking your medicines?	<input type="checkbox"/>	<input type="checkbox"/>
26	Do you drink something (e.g. water) whilst taking your medicines?	<input type="checkbox"/>	<input type="checkbox"/>
27	Does the medicine ever go down the wrong way causing you to choke?	<input type="checkbox"/>	<input type="checkbox"/>

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We now have a few questions on your daily routine with your medicines:		Never	Rarely	Sometimes	Often	Very often
28	If I get side effects from a drug, I stop taking it for good	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29	If I get side effects from a drug, I stop taking it for a while (days or weeks)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30	If my disease gets worse, I increase the dose of the drug for this disease myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31	When a drug has no effect, I stop taking it for good	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32	If necessary, I take an extra-dose or miss out a dose (e.g. miss a water tablet because of a journey)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33	If my disease gets better, I stop taking the respective drug for good	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34	If my disease gets better, I stop taking the respective drug for a while (days or weeks)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35	If the costs or co-payment of my drug is too high, I stop taking it for good	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36	I take my medication less often or stop taking it for a while to make the package last longer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37	If I do not manage to get my prescription refilled on time, I stop taking my drug for a while	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38	I do not take my drug at all, because in my opinion it is not good to treat each disease with drugs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39	Now and then I stop taking my drug for a while since I dislike taking drugs all the time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40	I forget to take my drug	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41	I am unable to take my drug due to my medical condition (e.g. because I am not able to open the package or swallow the tablet)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

You have reached the end of the questionnaire. Thank you so much for taking part! Please return this questionnaire and the study documents to the researcher or alternatively return it in the stamped addressed envelope provided to the study team here at University College Cork.

Appendix B: Data collection form evaluating each item/question (Q), response format, and instructions of the SWAMECO questionnaire.

	Clarity Mark: C for Clear; U for Unclear			
	ITEM/QUESTION	RESPONSE FORMAT	INSTRUCTIONS	ALTERNATIVE SUGGESTION
General Instructions				
Q1				
Q2				
Q3				

Appendix C: Data collection form for healthcare professionals evaluating the relevance of each question (Q) of the SWAMECO questionnaire.

	Relevance: 1= not relevant; 2 = unable to assess relevance; 3 = relevant but needs minor alteration; 4 = very relevant and succinct	Suggestion to improve relevance
General Instructions		
Q1		
Q2		
Q3		

APPENDIX D: Guide for interview

The proposed topic guide for the interviews is detailed below. These are the suggested guidelines for the discussion but as with other qualitative research forms the progression of the interview will be determined by the participant. In addition, the topic guide for future participants will undergo revision based on the themes emerging in earlier interviews.

1. Complete "Data Collection Form- Clarity of Instrument"
Remember- look for alternative suggestions for any item rated as unclear
2. General comments about the questionnaire?
3. Discuss the questionnaire in general- was it acceptable, easy to complete, useful...?
4. Any suggestions about how to improve the questionnaire?
5. Any further comments/ feedback/ suggestions?

Additional questions for HCPs:

Complete "Data Collection Form- Content Validity"

Remember- look for suggestions to improve relevance if necessary

Do you think the questionnaire is appropriate?

Query face validity of the questionnaire?

APPENDIX E: Pilot tested version of the SWAMECO questionnaire in English



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Dear participant

This questionnaire was developed to find out and to understand how people with swallowing difficulties deal with taking medicines. Our aim is that by using these results we will be able to recognise patients with swallowing difficulties at an earlier stage and therefore improve patient safety and quality of life. Swallowing difficulties affect people in different ways. Due to this, there are no right or wrong answers. All the answers and details you give will be anonymised so that there is no chance any of the details can be attributed to you.

The questionnaire has 28 questions over four pages and will take approximately 10 minutes to complete. Most of the questions are phrased so that you choose your answer by putting an "X" in the box. Unless the question mentions a different way of answering it, we would be grateful if you could answer just by using the "X" in the relevant box.

Once you have completed the questionnaire, please return it to the researcher or alternatively return it in the stamped addressed envelope provided to the study team at University College Cork.

Thank you so much for participating!

Personal details

ID:		Year of Birth:		Sex:	<input type="checkbox"/> Female
					<input type="checkbox"/> Male

		Yes	No
1	Currently, do you take at least one medicine that you have to swallow?	<input type="checkbox"/>	<input type="checkbox"/>

Do you experience swallowing difficulties...		Yes, currently	Yes, in the past	No, never
2	... when you drink?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	... when you eat?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	... when you take your medicines?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you have answered "Yes" to any of the questions 2,3 or 4, then please go to Question 5 on page 2.

If you have answered "No" to all of the questions 2,3 and 4 then please go to Question 17 on page 3.

Please read the following statements and put an "X" in the box which represents your view most closely:


		Strongly agree	Agree	Disagree	Strongly disagree	Not applicable
5	Swallowing medicines used to, or still causes me, to feel like I am....					
5.1	... choking.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.2	... having a fit of coughing.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.3	... going to gag or be sick.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.4	... having difficulty breathing like a tightness in the chest.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	Often I have a dry mouth during the day.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
7	Often I have an unpleasant burning sensation in my mouth.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
8	My eyes and/or my nostrils often feel dry.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
9	I have the feeling that my medicines get stuck in my throat.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10	Swallowing medicines causes pain.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11	In the last four weeks I have been worried about my swallowing difficulties.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12	Sometimes I will purposely not take a medicine because taking it will cause me swallowing difficulties.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13	As a result of my swallowing difficulties I am afraid of the next time I have to take my medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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14

Think of a time you had to take a medicine which caused you swallowing difficulties. Mark on the line below with an "X" between 0 and 10, how much discomfort you felt.

0 10



(0 = no discomfort)



(10 = unbearable discomfort)

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15 In the diagram below, please mark with an "X" where you have had, or still have, swallowing difficulties when you take your medicines.
(There may be more than one "X" and more than one answer to this question)

Describe how this feels
(e.g. the capsule gets stuck, pain, need to cough)

16 Which of your medicine(s) caused these swallowing difficulties?
(please give details of the name and the dose e.g. Nuseals Aspirin 75mg, 1 to be taken daily)

17 How would you describe the position of your head as you swallow your medicines?

Head tilted slightly forward	Head straight	Head tilted slightly back
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

18 Have you ever modified your medicine in any way, shape or form, to make it easier to take?

Yes	No
<input type="checkbox"/>	<input type="checkbox"/>
Please go to Question 19	Please go to Question 21

19 Please describe how you have modified the medicine (more than one answer is possible):

Splitting tablets Opening capsules Chewing tablets

Crushing tablets Dispersing tablets in a liquid

Other please describe:
.....

Please describe what you do using key words / short notes

20 Did you ask your doctor or pharmacist for advice before you modified your medicine(s)?

Yes	No
<input type="checkbox"/>	<input type="checkbox"/>

		Yes	No
21	Has your doctor ever asked you about swallowing difficulties?	<input type="checkbox"/>	<input type="checkbox"/>
22	Has your pharmacist ever asked you about swallowing difficulties?	<input type="checkbox"/>	<input type="checkbox"/>
23	Has your doctor or pharmacist ever offered you a different formulation (syrup, liquid, smaller tablets) instead of the tablets or capsules you receive?	<input type="checkbox"/>	<input type="checkbox"/>
24	Do you eat something (e.g. yoghurt) to help you swallow the medicine?	<input type="checkbox"/>	<input type="checkbox"/>
25	Do you drink something (e.g. water) to help you swallow the medicine?	<input type="checkbox"/>	<input type="checkbox"/>

We now have a few questions on your daily routine with your medicines:

26	<p>In the last 30 days, on how many days did you miss at least one dose of any of your medicines?</p> <p>Write in number of days: _____ (0-30)</p>
----	--

27	<p>In the last 30 days, how good a job did you do at taking your medicines in the way you were supposed to?</p> <p><input type="checkbox"/> very poor <input type="checkbox"/> poor <input type="checkbox"/> fair</p> <p><input type="checkbox"/> good <input type="checkbox"/> very good <input type="checkbox"/> excellent</p>
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28	<p>In the last 30 days, how often did you take your medicines in the way you were supposed to?</p> <p><input type="checkbox"/> never <input type="checkbox"/> rarely <input type="checkbox"/> sometimes</p> <p><input type="checkbox"/> usually <input type="checkbox"/> almost always <input type="checkbox"/> always</p>
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Any other comments:

You have reached the end of the questionnaire. **Thank you so much for taking part!** Please return this questionnaire and the study documents to the researcher or alternatively return it in the stamped addressed envelope provided to the study team here at University College Cork.