**ALSAQ : Concept Elaboration Report**

PharmaQuest Ltd. produced a concept elaboration document that defined each item of the ALSAQ-40 and the conceptual meaning behind each item. This document shown below was approved by the instrument developer and aimed to clarify any possible ambiguities or nuances before any translation work began.

|  |  |  |  |
| --- | --- | --- | --- |
| **Ref** | **Questionnaire  Wording** | **Concept Elaboration** | **Developer’s  Comments** |
| 1 | **Please complete this questionnaire as soon as possible.** | This line asks the respondent to fill in the questionnaire as soon as possible. Please note, this does not refer to the speed at which the respondent should fill in the questionnaire; it refers to the amount of time between receiving the questionnaire and filling it in.  ‘Complete’ is used as a synonym of ‘fill in’, and ‘fill in’ may be used if it is more idiomatic in the target language in this context. | **Developer:** OK |

|  |  |  |  |
| --- | --- | --- | --- |
| 2 | If you have any difficulties filling in the questionnaire by yourself, please get someone else to help you with it. | If the respondent has any difficulties/problems filling in the questionnaire (marking their answers) alone, they should do so with the help of another person. | **Developer:** OK |
| 3 | However it is **your** responses that we are interested in. | Regardless of whether the respondent receives help to fill in the questionnaire, the people issuing the questionnaire are interested in the respondent’s own responses. | **Developer:** OK |
| 4 | The questionnaire consists of a number of statements about difficulties that you may have experienced **during the last 2 weeks.** | The questionnaire consists of/is made up of a number of statements. These statements are about/concern difficulties the respondent may have experienced/had during the past 2 weeks.  This refers to the past 14 days leading up to today, not necessarily the past two calendar weeks from Monday to Sunday. | **Developer:** OK |
| 5 | There are no right or wrong answers: your first response is likely to be the most accurate for you. | This informs the respondent that their answers cannot be interpreted as correct or incorrect; in other words, the respondent’s personal opinion is what is important.  This assertion is explained further by stating that the respondent’s first response (the answer they think of first) is likely/probable to be the most accurate answer for them. | **Developer:** OK |

|  |  |  |  |
| --- | --- | --- | --- |
| 6 | **Please tick the box which best describes your own experience or feelings.** | The respondent is asked to enter a tick/checkmark () in the box corresponding to the answer that best describes their own experience or feelings. Please note, ‘feelings’ can be either physical or emotional; if possible a term should be used for ‘feelings’ that does not exclude either aspect. If it is more common in the target country to enter a cross (X) than a tick, then the wording may be amended accordingly to refer to ‘cross’. | **Developer:**  OK (i.e. happy with ‘X’ in appropriate countries) |
| 7 | **Please try to answer every question** even though some may seem rather similar to others, or may not seem relevant to you. | The respondent should attempt/do their best to respond to every question, even though (despite the fact) that some of them may seem quite similar to others, or they may not seem relevant/pertinent/appli cable to the respondent. | **Developer:** OK |
| 8 | All the information you give will be treated in the **strictest confidence**. | All the information that the respondent gives/provides will be treated as strictly confidential; i.e., no information about the respondent will be shared with anyone other than the relevant parties. | **Developer:**  I’d stress that this also means that there will be no way of tracing responses to any specific individual. |
| 9 | The following statements all refer to difficulties that you may have had **during the last 2 weeks**. | The statements that follow all refer to/are about difficulties that the respondent may have had/experienced during the past 2 weeks (14 days leading up to today).  Please note that this | **Developer:** OK |
|  |  | refers to the statements on the next few pages, so translators should avoid using ‘below’ for ‘following’. |  |
| **10\*** | Please indicate, by ticking the appropriate box, how often the following statements have been true for you. | The respondent should enter a tick/checkmark () (or box in the relevant countries) in the appropriate box to indicate how often/frequently the following statements have been true for them during the past 2 weeks – in other words, how often the respondent’s situation or experience has matched what is described in the statement. | **Developer:** OK |
| 11 | ALSAQ-5 © Isis Innovation Limited, 2000.All rights reserved. /  ALSAQ-40 © Isis Innovation Limited, 2000. All rights reserved. | This is a copyright notice, stating that the copyright for the ALSAQ-5 or ALSAQ-40 is held by Isis Innovation Limited. All rights associated with the copyright are reserved by the copyright holder.  **Note to Developer:** Please could you advise whether you would like us to translate ‘All rights reserved.’, or whether the whole copyright line should remain in English? | **Developer:**  The copyright line should remain in English.  **PharmaQuest:**  This line will be left in English and omitted from further reports. |
| **12\*** | ***The following statements all refer to certain difficulties that you may have had during the last 2 weeks*** | The statements that follow all refer to/are about certain/particular difficulties that the respondent may have had/experienced during the past 2 weeks (14 days leading up to today). | **Developer:** OK |
|  |
|  |
| 13 | If you cannot walk at all please tick | If the respondent is not able to walk at all, they | **Developer:** OK |
|  | ***Always/cannot walk at all****.* | should enter a tick/checkmark () (or cross if appropriate for the target country) in the box corresponding to the option ‘Always/cannot walk at all’. |  |
|  |  | **Note to Developer:** | Yes, please harmonise |
|  |  | In this item, there is a slash after ‘Always’, but in the response option it | (with ‘or’)  **PharmaQuest:** |
|  |  | is written out as ‘or’ (please see item 17 | Thank you; item to be worded as follows: |
|  |  | below). Please could you advise whether you would like us to harmonise this by replacing the slash with | If you cannot walk at all please tick ***Always or cannot walk at all****.* |
|  |  | ‘or’ in this item? |  |
| **14\*** | ***How often during the*** | This asks how | **Developer:** |
|  | ***last 2 weeks have the*** | often/frequently the following (statements) have been true for the respondent during the past 2 weeks (14 days leading up to today) – in other words, how often the respondent’s situation or experience has matched what is described in the statement. | OK |
| ***following been true?*** |
| **15\*** | *Please tick* ***one box*** *for* | The respondent should | **Developer:** |
|  | *each question* | enter a tick/checkmark/cross | OK |
|  |  | (as applicable) in one box for every question. |  |
| **16** | **I have found it** | The respondent has | **Developer:** |
| **Q1** | **difficult to walk short distances, e.g. around the house.** | found it difficult to walk short distances – for example, to walk between rooms in the house. | OK |
| **17** | **Never** | These are the response | **Developer:** |
| **R1-** | **Rarely** | options . The first 4 | OK |
| **40** | **Sometimes Often** | options are used for every question, 1 to 40. |  |
|  | **Always or cannot walk at all** | The last one is used for questions 1-5. Further |  |
|  |  | response options are shown further below (24 and 50). |  |
|  |  | Never – not at any time |  |
|  |  | (during the past 2 weeks) |  |
|  |  | Rarely – infrequently. |  |
|  |  | Sometimes – this should be translated as a half­way point between |  |
|  |  | ‘rarely’ and ‘often’. |  |
|  |  | Often – frequently |  |
|  |  | Always or cannot walk at all – the respondent experiences the difficulty/situation all the time, or they are not able to walk at all. |  |
| **18** | **I have fallen over** | The respondent has | **Developer:** |
| **Q2** | **whilst walking.** | fallen over while they were walking. This refers to falling onto the ground, as opposed to tripping, as in the next statement. | OK |
| **19** | **I have stumbled or** | The respondent has | **Developer:** |
| **Q3** | **tripped whilst walking.** | stumbled or tripped while they were walking. | OK |
|  |  | These two terms are almost synonymous – |  |
|  |  | ‘stumbling’ refers to walking unsteadily, misplacing the feet, having trouble walking upright, etc. ‘Tripping’ refers to striking the foot against something, causing the walker to lose balance. |  |
|  |  | ‘Stumbling’ can also incorporate ‘tripping’. |  |
| **20** | **I have lost my** | The respondent has lost | **Developer:** |
| **Q4** | **balance whilst walking.** | (not been able to maintain) their balance while they were walking. | OK |
| **21** | **I have had to** | The respondent has had | **Developer:** |
| **Q5** | **concentrate whilst** | to/needed to | i.e. they have needed to |
|  | **walking.** | concentrate while they  were walking (in order  to keep their balance, | think about walking in order to achieve it. |

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | avoid stumbling, etc.). |  |
| **22\*** | *Please make sure that* | The respondent should | **Developer:** |
|  | *you have ticked* ***one box for each question*** *before going on to the next page.* | make sure/ensure that they have entered a tick/checkmark/cross (as appropriate) in one box for every question before they move ahead to the following page. | OK |
| **23\*** | If you cannot do the | If the respondent cannot | **Developer:** |
|  | activity at all please tick | do the activity described | Yes, please insert ‘or’ |
|  | ***Always/cannot do at all.*** | in the statement at all, they should tick the last option, ‘Always/cannot | and remove slash **PharmaQuest:** |
|  |  | do at all’. | Thank you; item to be worded as follows: |
|  |  | **Note to Developer:** |  |
|  |  | In this item, there is a slash after ‘Always’, but in the response option it is written out as ‘or’ | If you cannot do the activity at all please tick ***Always or cannot do at all.*** |
|  |  | (please see item 24 below). Please could you advise whether you would like us to harmonise this by replacing the slash with |  |
|  |  | ‘or’ in this item? |  |
| **24\*** | **Always or cannot do** | This is a response | **Developer:** |
| **R6-** | **at all** | option that is used for | OK |
| **30** |  | questions 6-30. |  |
|  |  | The statement is always true for the respondent, or they cannot do the activity mentioned at all. |  |
| **25** | **Walking has tired me** | Walking has tired | **Developer:** |
| **Q6** | **out.** | out/worn out the respondent/made the respondent tired. | The mere act of walking has caused tiredness, irrespective of distance walked |
| **26** | **I have had pains in** | The respondent has | **Developer:** |
| **Q7** | **my legs whilst walking.** | experienced pains in their legs while they were walking. | OK |
| **27** | **I have found it** | The respondent has | **Developer:** |
| **Q8** | **difficult to go up and down the stairs.** | found it difficult to walk up and down stairs. | OK |
| **28** | **I have found it** | The respondent has | **Developer:** |
| **Q9** | **difficult to stand up.** | found it difficult to stand up – moving into a | OK |

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | standing position from either sitting or lying down. |  |
| **29** | **I have found it** | The respondent has | **Developer:** |
| **Q10** | **difficult to get myself up out of chairs.** | found it difficult to get up (raise the body up to a standing position) from chairs. | OK |
| **30** | **I have had difficulty** | The respondent has | **Developer:** |
| **Q11** | **using my arms and** | experienced difficulties | i.e. has limited control |
|  | **hands.** | in using their arms and hands. | over the movement of their arms and hands |
| **31** | **I have found turning** | The respondent has | **Developer:** |
| **Q12** | **and moving in bed difficult.** | found it difficult, when they are in bed, to turn/roll over and to move. This refers to difficulty moving when laying down in bed. | OK |
| **32** | **I have found picking** | The respondent has | **Developer:** |
| **Q13** | **things up difficult.** | found it difficult to pick things/objects up (to grasp it in the hand or hands and lift it). This refers to difficulty grasping things rather than lifting heavy items. | OK |
| **33** | **I have found holding** | The respondent has | **Developer:** |
| **Q14** | **books or newspapers, or turning pages, difficult.** | found it difficult to hold books or newspapers, or to turn over the pages. | OK |
|  |  | This refers to manual dexterity and the ability to hold an object in one position for any length of time. |  |
| **34** | **I have had difficulty** | The respondent has | **Developer:** |
| **Q15** | **writing clearly.** | found it difficult to write in a clear, legible way. | OK |
| **35** | **I have found it** | The respondent has | **Developer:** |
| **Q16** | **difficult to do jobs around the house.** | found it difficult to carry out jobs/tasks around the house. This could include maintenance jobs (mending things), decoration, cleaning, cooking, etc. | OK |
| **36** | **I have found it** | The respondent has | **Developer:** |
| **Q17** | **difficult to feed** | found it difficult to feed | Yes, this refers to the |
|  | **myself.** | themselves. | activity of eating, including cutting up, |

14

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Note to Developer:** Please could you advise whether this refers solely to the act of eating, or whether it also includes cooking, food preparation and possibly food shopping? | chewing, and swallowing food. It does not refer to food preparation. |
| **37** | **I have had difficulty** | The respondent has | **Developer:** |
| **Q18** | **combing my hair or cleaning my teeth.** | found it difficult to comb/brush their hair | OK |
|  |  | (to groom their hair with a hairbrush or comb) or to clean/brush their teeth (with a toothbrush). |  |
| **38** | **I have had difficulty** | The respondent has | **Developer:** |
| **Q19** | **getting dressed.** | found it difficult to get dressed/put on clothes. | OK |
| **39** | **I have had difficulty** | The respondent has | **Developer:** |
| **Q20** | **washing at the hand** | found it difficult to wash | OK (though basin does |
|  | **basin.** | their hands and face at  the hand basin (i.e., the  basin in the bathroom). | not have to be in a bathroom) |
| **40** | **I have had difficulty** | The respondent has | **Developer:** |
| **Q21** | **swallowing.** | found it difficult to swallow (this could refer to saliva, food or drinks). | OK |
| **41** | **I have had difficulty** | The respondent has | **Developer:** |
| **Q22** | **eating solid food.** | found it difficult to eat solid food. | OK |
| **42** | **I have found it** | The respondent has | **Developer:** |
| **Q23** | **difficult to drink** | found it difficult to drink | OK (refers primarily to |
|  | **liquids.** | liquids. | the ability to swallow) |
| **43** | **I have found it** | The respondent has | **Developer:** |
| **Q24** | **difficult to participate** | found it difficult to take | OK (primarily because |
|  | **in conversations.** | part in conversations. | of difficulty with speech) |
| **44** | **I have felt that my** | The respondent has | **Developer:** |
| **Q25** | **speech has not been easy to understand.** | felt/thought that their speech/talking has not been easy for other people to understand. | OK |
| **45** | **I have slurred or** | The respondent has | **Developer:** |
| **Q26** | **stuttered whilst speaking.** | slurred their words or stuttered while they were speaking. ‘Slurring’ is what happens when words are not pronounced clearly, particularly when the | OK |
|  |  | consonants are not clearly spoken. ‘Stuttering’ (also called ‘stammering’) refers to the repetition of the first sound of the word. |  |
| **46** | **I have had to talk** | The respondent has had | **Developer:** |
| **Q27** | **very slowly.** | to/needed to talk very slowly (in order to be understood). | OK |
| **47** | **I have talked less** | The respondent has | **Developer:** |
| **Q28** | **than I used to do.** | talked less (during the past 2 weeks) than they used to talk. The timeframe that ‘used to’ refers to is unspecified, but it can be assumed that it refers to a time before the respondent became ill, or when their symptoms were milder. | OK |
| **48** | **I have been** | The respondent has | **Developer:** |
| **Q29** | **frustrated by my** | been frustrated | In this context |
|  | **speech.** | by/about their speech – it has made them irritable/angry/agitated/ annoyed due to the | ‘frustrated’ could be substituted by ‘irritated’  **PharmaQuest:** |
|  |  | difficulties. ‘Frustration’ relates to the feeling of wanting to do something (in this case, speak clearly) and being unable to do so. | Thank you. For languages where a direct translation of ‘frustrated’ does not exist, we will use ‘irritated’. |
| **49** | **I have felt self-** | The respondent has felt | **Developer:** |
| **Q30** | **conscious about my speech.** | self-conscious about their speech. This refers to being particularly aware of their speech when around other people, and being particularly aware of other people’s reactions to it. | OK |
| **50** | **Always** | This is another response | **Developer:** |
| **R31** |  | option, that is used for | This is the fifth response |
| **-40** |  | questions 31-40. | option (instead of |
|  |  | Always – the statement has been true for the respondent all the time | ‘Always or cannot do at all’ used for the preceding questions) |

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | during the past 2 weeks. |  |
| **51** | **I have felt lonely.** | The respondent has felt | **Developer:** |
| **Q31** |  | lonely/alone. | OK |
| **52** | **I have been bored.** | The respondent has | **Developer:** |
| **Q32** |  | been bored – this could refer to a lack of external stimulus to keep the respondent interested (social contact, interesting work, entertainment, etc.) or it could refer to the respondent’s lack of interest in their surroundings. | I am not sure it is helpful to speculate as to the cause of the boredom, though most likely it is because they cannot engage fully with the physical and social world |
| **53** | **I have felt** | The respondent has felt | **Developer:** |
| **Q33** | **embarrassed in social situations.** | embarrassed in situations where they may be expected to or wish to interact with other people. | OK |
|  |  | ‘Embarrassed’ refers to feeling highly self-conscious and concerned with others’ perception of oneself, and includes a feeling of unwanted exposure in front of other people. |  |
| **54** | **I have felt hopeless** | The respondent has felt | **Developer:** |
| **Q34** | **about the future.** | hopeless/had no hopes for the future. | Felt the future offered no hope. |
| **55** | **I have worried that I** | The respondent has | **Developer:** |
| **Q35** | **am a burden to other people.** | worried/been concerned that they may be a burden to other people. | OK |
|  |  | A burden is something that is borne (carried, figuratively) with difficulty, so effectively the respondent is worried about causing difficulties for other people due to their condition. |  |
| **56** | **I have wondered why** | The respondent has | **Developer:** |
| **Q36** | **I keep going.** | wondered/asked themselves why they keep going/carry on/continue. | OK |
|  |  | The meaning of this item is not explicit but the implication is that it refers to carrying on with daily life with a disease which is degenerative. This statement must be phrased in a sensitive way so as to avoid offending respondents. |  |
| **57** | **I have felt angry** | The respondent has felt | **Developer:** |
| **Q37** | **because of the disease.** | angry because of the disease/illness. | OK |
| **58** | **I have felt depressed.** | The respondent has felt | **Developer:** |
| **Q38** |  | depressed/low/down. | OK |
|  |  | Please note that ‘feeling depressed’ is different to |  |
|  |  | ‘being depressed’; the first is a mental state whereas the second implies a formal diagnosis. It is important to retain the reference to ‘felt’ if possible. |  |
| **59** | **I have worried about** | The respondent has | **Developer:** |
| **Q39** | **how the disease will affect me in the future.** | worried/been concerned about the way(s) in which the disease/illness will affect them in the future. | OK |
| **60** | **I have felt as if I have** | The respondent has felt | **Developer:** |
| **Q40** | **no freedom.** | as though they do not have any freedom. This refers to the restrictive nature of the disease/illness. | OK |
| 61 | *Please make sure that* | The respondent should | **Developer:** |
|  | *you have ticked* ***one box for each question.*** | make sure/ensure that they have entered a tick/checkmark/cross | OK |
|  |  | (as appropriate) in one box for every question. |  |
| 62 | ***Thank you for*** | This line thanks the | **Developer:** |
|  | ***completing this questionnaire.*** | respondent for filling in the questionnaire. | OK |