

Today's date:

d d

m m

y y y y

Participant ID:

Cen

Pat

# PUQALY – Valuing quality of life after pressure ulcers

## Interview Schedule A

Please read out to the participant:

*“Thank you for agreeing to participate in this research. The research aims to help better understand how pressure ulcers impact on people’s quality of life. During the interview you will be asked a number of questions that aim to get you thinking about how severe the impact of pressure ulcers are and ways in which they can affect on an individual’s life”*

*...Please answer all of the questions you feel able to. There are no right or wrong answers. All of your responses are anonymous and confidential and **will not** affect any treatment you receive in the future. The interview should last about 30-45 minutes. However, you are free to stop the interview at any time and withdraw from the study. Please ask for clarification if you do not understand a question”*

## Section 1: Demographic questions

1. What is your date of birth?

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
d	d	m	m	y	y

2. Are you? (*please tick one*):       Male       Female

3. How many children do you have (under 18)?

4. Which ethnic group do you belong to? (*please tick only one*)

- |   |   |
|---|---|
| <input type="checkbox"/> White                  | <input type="checkbox"/> Mixed ethnicity    |
| <input type="checkbox"/> Asian or Asian British | <input type="checkbox"/> Gypsy / traveller  |
| <input type="checkbox"/> Black or Black British | <input type="checkbox"/> Other ethnic group |
| <input type="checkbox"/> Chinese                |   |

5. What is the highest level of education you have completed? (*please tick only one*)

- University or college or equivalent
- Intermediate between secondary level and university   
(e.g. technical training)
- Secondary school
- Primary school (or less)

## Section 2: Health questions

6. Do you have any medical conditions, illnesses or disabilities?

Yes  No

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Do you currently have, or have you had, any of the following health conditions? **CIRCLE**

**AS MANY ANSWERS AS ARE APPROPRIATE FOR YOU**

- |   |                                   |
|---|-----------------------------------|
| 1. Arthritis                                | 6. Hypertension                   |
| 2. Cancer                                   | 7. Stroke                         |
| 3. Chronic Obstructive Pulmonary<br>Disease | 8. Depression                     |
| 4. Diabetes                                 | 9. Other mental health conditions |
| 5. Heart disease                            | 10. Other health conditions       |
|   | 11. None of these conditions      |

Other please list:

7. How would you rate your overall health at the moment? *(Please tick one)*

Very poor	Poor	Fair	Good	Very good
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Section 3: Time Trade Off

Test TTO

*“I’m going to ask you to complete a task called ‘Time-trade-off’ which will tell us how bad you think it would be to live with pressure ulcers of varying severity. I’m going to ask you to complete a series of [9-11] TTO questions. In each case I’m going to show you a health situation on a card describing different effects and severity of pressure ulcers (also known as bed sores). Although they look similar, each scenario is different in some way. The other card is called full health and is Life A and is represented on a pink card The health condition with pressure ulcers in called Life B and is represented on green cards. . Full health is defined here as not having any bother with the health problems described on the green cards. Although it sounds strange, in this hypothetical task I want you to imagine that you only have 10 years to live.”*

Show participant Scenario Green Card life B

*“I’d like you to imagine that you were living in this health scenario and you had to live in it for the last 10 years of your life. Then I want you to imagine that you have a choice: you can either live in the scenario described in Life B for those remaining 10 years of your life or you can live for a shorter period of time, for example 5 years, but without the health problems described in Life A. So if you had 10 years left to live, would you prefer to live for those 10 years in the situation on card X or for 5 years but in normal health? (after the fifth year you would die)”*

Use the ping-pong method from this point on to arrive at the participant’s point of indifference as per training received.

Please ask participant to complete the [8-9] TTO tasks/cards

*(The screen has the colours pink for full health and green for the pressure ulcer health state)*

*“First I’d like to ask you to make a choice between Full health which is life A (read out if required pink card A) and the life with a pressure ulcer which we have called life B (on the green card). On the computer screen, the two scales show the number of years you would live in each health state.*

Q 1 At the moment, each scale says 10 years. This means that you would either live in Life A for 10 years and then die or you would live in Life B for 10 years and then die. Would you prefer Life A or Life B or are they the same?

- If Life A is chosen go to Q 4
- If Life B is chosen go to Q 2
- If it is the same go to Q 3

Q 2 Does this mean that you would rather live in Life B for 10 years than in Life A for 10 years?

- If yes, save the values 10 for the Full Health and 10 years for the Health State x, (are they timed – if so then start a new clock)
- If no (first time) repeat Q 1
- If no (second time after repeating Q1) go to Q 4

Q 3 Does this mean that living in Life B for 10 years would be the same as living in Life A for 10 years?

- If yes, save the values (10 years for the Full Health and 10 years for Health State X, (if timed clock stops and new card)
- If no (first time) repeat Q 1
- If no (second time) go to Q 4

Q 4 Now you would either die immediately, or you would live in Life B for 10 years and then die. Would you prefer to die immediately or to live Life B, or are they the same?

(the screen shows Life A at 0 years and Life B at 10 years)

Choice of Life A; Life B: or The same

- If Life A, go to Q 9
- If Life B, go to Q 5

- If the same, save the values (0 for Full health and 10 years for Health State x) (Stop and start a new card)

Q 5 Now you would either live in Life A for 5 years and then die or you would live in Life B for 10 years and then die. Would you prefer Life A or Life B, or they the same?

(The screen shows Life A at 5 years and Life B at 10 years)

- If Life A, the cursor will move one notch to the left becoming 4 years. Go to Q6.
- If Life B, the cursor will move one notch to the right i.e. becoming 6 years. Go to Q7.
- If the same, save the values 5 years for Full health and 10 years for health state X. Stop and start a new TTO exercise card.

Q 6 Now you would either live in Life A for (updated number ) years and then die or you would live in Life B for 10 years and then die or are they the same?

- If Life A, the cursor will move one notch to the left. Repeat Q 6 until the respondent answers “Life B” or the “Same”. If the marker is at zero, repeat Q6, if Life A is chosen go to Q 9 (the cursor can go further to the left), if Life B is chosen do the second bullet point of Q 6, if the same do the third bullet point of Q6
- If Life B is chosen, the cursor will move one half notch to the right. Go to Q 8
- If the same, save the values (updated number from screen) years and 10 years for health state x, stop and start new TTO card.

Q7. Now you would either live in Life A for (updated number) years and then die or you would live in Life B for 10 years and then die, Would you prefer Life A or Life B or are they the same?

- If Life A, the cursor will move one half notch to the left, go to Q8.
- If Life B, the cursor will move one notch to the right. Repeat Q7 until
  - a. If respondent answers “Life A GO TO Q8. If the respondent answers ”Same” – save the value and start a new TTO exercise Card.
  - b. If respondent answers Life B and the marker is on 9 years then the marker moves up to 9 years 3 months, 9 years 6 months, 9 years 9 months, 9 years 11 months.
- If the same, save the values (updated number) for Full Health and 10 years for health state x), Stop and start a new TTO exercise.

Q8. Now you would either life in Life A for (updated number) of years and then die or you would life in Life B for 10 years and then die. Would you prefer to have Life B or are they the same?

- If Life A, save the values (updated number in years and months) for Full Health and 10 years for Health State x, stop and start a new TTO exercise.
- If Life B, save the values (updated number in years and months) for Full Health and 10 years for Health State x. Stop and start a new TTO exercise.
- If “same”, save the values (updated number in years and months) for Full Health and 10 years for Health State x) Stop and start a new TTO exercise.

Q 9 (If always choose Life A) Does this mean that you would rather die immediately than life in Life B for 10 years?

- If yes go to Q11
- If no go to Q 4.

Q10 (If always chooses Life B) What if you would either live in Life A for 9 years 3,6,9,11 months and then die or live in Life B for 10 years? Would you prefer Life A or Life B or are they the same?

- If Life A, save the values (updated number) for Full Health and 10 years for Health State X. Stop and start a new TTO exercise.
- If Life B, save the values (updated number in years and months) for Full Health and 10 years for Health State x. Stop and start a new TTO exercise.
- If “same”, save the values (updated number in years and months) for Full Health and 10 years for Health State x) Stop and start a new TTO exercise for Health State x. Stop and start a new TTO exercise.

TTO answer table

Scenario	TTO response – point of indifference (years, months)
1	
2	
3	
4	

5	
6	
7	
8	
9	
10	
11	

Did the participant appear to understand the TTO?

Yes     No     Unsure

### Section 4: Ranking task

Please take a look at the scenario cards; these are the scenarios you have just been considering in the time trade-off task. We have added to scenarios to this – one is ‘death’ and one is your own health state at the moment.

We would like you to think about these health scenarios and try to put them in order of severity – i.e. arrange the cards so that they range from the most severe to the least severe in your opinion.

When you have sorted the cards please enter the order of the scenario cards onto the computer.

Now I would like you to rate the severity of each scenario from 0 to 100 with 0 being the worst health you can imagine and 100 representing Full health. If you think that two scenarios would have the same score then that is fine. Please enter the values you gave for each scenario onto the computer.

Please make a note of the order and rating for each scenario

Scenario	Ranking (1-12 or 13) 1 is worst	Rating (0-100)
1		
2		
3		
4		

5		
6		
7		
8		
9		
10		
11		
Death		
Own health state		

Did the participant appear to understand the ranking task?

Yes    No    Unsure

### **Section 5: EQ-5D**

*[NB: The EQ-5D instrument was collected however the instrument is omitted due to copyright. The EQ-5D instrument can be obtained from URL: <http://www.euroqol.org/>].*



Health rating scale

**Full health**



**Worst  
imaginable  
health**

**Thank participant for helping with the research and reiterate assurances about confidentiality and anonymity. Ask if they have any questions.**