



PURPOSE

Pressure Ulcer Quality Adjusted Life Years (PUQALY): An Item Reduction Survey

To the Researcher:

This survey should be administered by you to the patient. Please read out the questions and record their responses. Sections A and B ask about the patient and their health. Section C is related to quality of life and Section D asks about health preferences.

Please provide clarifications and explanations of questions if they are not clear to the patient. However, the responses should be those of the patient. Please refer to the PUQoLI user manual if necessary.

Researcher to read out to the patient:

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. This survey asks a number of questions that aim to get you thinking about the impact of your pressure ulcer(s) and ways in which they affect your 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 survey should take about 20-30 minutes to complete. However, you are free to stop participating at any time and withdraw from the study. Please ask for clarification if you do not understand a question

Section A: About You

1. Patient's date of birth

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2. Gender (*please tick one*):

Male

Female

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

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

White

Mixed ethnicity

Asian or Asian British

Other ethnic group

Black or Black British

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 B: Your Health

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

Yes No

If 'Yes', please list your other illnesses or disabilities:

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2. Are you a wheelchair user?

Yes

No

3. How long have you had your pressure ulcer(s)?

Weeks Months Years

4. On which part of your body do you have pressure ulcer(s)?

(please tick)

Area at the bottom of your spine	<input type="checkbox"/>	Ankle/Foot	<input type="checkbox"/>
Buttocks	<input type="checkbox"/>	Heel	<input type="checkbox"/>
Back of leg and/or thigh	<input type="checkbox"/>	Elbow	<input type="checkbox"/>
Hip	<input type="checkbox"/>	Head and/or face	<input type="checkbox"/>

Other Please specify:

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5. What is the patient's clinical pressure ulcer grade? *(Please tick one)*

Grade 1	Grade 2	Grade 3	Grade 4
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. How severe would you say your pressure ulcer(s) are at the moment? *(Please tick one)*

Very severe	severe	Moderate	Mild	Very mild
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. Apart from your pressure ulcer do you have any other type of wounds or ulcers (such as diabetic foot ulcer or venous leg wound) at the moment?

Yes No

8. Thinking about your health (including your pressure ulcer(s) and all other health problems).

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"/>

9. Please now **imagine** that you did not have a pressure ulcer. How would you rate your health at the moment if you did not have the pressure ulcer (but still had the other health problems)?

(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 C: Quality of Life

In this section please complete the following questions which ask about your general health and your pressure sore(s) and how they have affected aspects of your everyday life over the past week.

[NB: The PU-QOL instrument was collected however the instrument is omitted due to copyright. The PU-QOL instrument can be obtained from URL: <http://medhealth.leeds.ac.uk/puqol-ques/>].

[NB: The PUQOL-UI instrument was collected however the instrument is omitted due to copyright. The PUQOL-UI instrument can be obtained from URL: <http://ctru.leeds.ac.uk/purpose/>].

Health rating scale

To help people say how good or bad their health state is we have drawn a scale (rather like a thermometer) on which the best health you can imagine is marked 100 and the worst health you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box to whichever point on the scale indicates how good or bad your health is today.

**Your own health
today**

Full health

100



0

**Worst
imaginable**

Section D: Your health preferences

This next section includes an **imaginary** exercise. Even though the questions may sound strange please do your best to answer. Your responses will give us an idea about how severe your current health problems are.

[to be read by the researcher]

For each question **imagine** that you have all your current health problems and are guaranteed to live for another ten years after which you would die or you could choose to live in full health but for less than 10 years.

For each set of options please tick **one** box to indicate which you would prefer.

1.	To live 10 years in your current health	<input type="checkbox"/>	7.	To live 10 years in your current health	<input type="checkbox"/>
	To live 9 years and 9 months in full health	<input type="checkbox"/>		To live 5 years in full health	<input type="checkbox"/>
2.	To live 10 years in your current health	<input type="checkbox"/>	8.	To live 10 years in your current health	<input type="checkbox"/>
	To live 9 years and 6 months in full health	<input type="checkbox"/>		To live 4 years in full health	<input type="checkbox"/>
3.	To live 10 years in your current health	<input type="checkbox"/>	9.	To live 10 years in your current health	<input type="checkbox"/>
	To live 9 years in full health	<input type="checkbox"/>		To live 3 years in full health	<input type="checkbox"/>
4.	To live 10 years in your current health	<input type="checkbox"/>	10.	To live 10 years in your current health	<input type="checkbox"/>
	To live 8 years in full health	<input type="checkbox"/>		To live 2 years in full health	<input type="checkbox"/>
5.	To live 10 years in your current health	<input type="checkbox"/>	11.	To live 10 years in your current health	<input type="checkbox"/>
	To live 7 years in full health	<input type="checkbox"/>		To live 1 year in full health	<input type="checkbox"/>

6.	To live 10 years in your current health	<input type="checkbox"/>		12.	To live 10 years in your current health	<input type="checkbox"/>
	To live 6 years in full health	<input type="checkbox"/>			To live 6 months in full health	<input type="checkbox"/>

If the patient gives an alternative amount of time please write this here:

.....

Please tick here if the patient did not understand this task:

For each question below **imagine** that your pressure ulcer had been cured. Then imagine that you have the choice between living for the next 10 years in your current health with your health problems but without a pressure ulcer (after which you would die) or living fewer years but in full health (after which you would die).

For each set of options please tick **one** box to indicate which you would prefer

1.	To live 10 years in your current health	<input type="checkbox"/>		7.	To live 10 years in your current health	<input type="checkbox"/>
	To live 9 years and 9 months in full health	<input type="checkbox"/>			To live 5 years in full health	<input type="checkbox"/>
2.	To live 10 years in your current health	<input type="checkbox"/>		8.	To live 10 years in your current health	<input type="checkbox"/>
	To live 9 years and 6 months in full health	<input type="checkbox"/>			To live 4 years in full health	<input type="checkbox"/>
3.	To live 10 years in your current health	<input type="checkbox"/>		9.	To live 10 years in your current health	<input type="checkbox"/>
	To live 9 years in full health	<input type="checkbox"/>			To live 3 years in full health	<input type="checkbox"/>
4.	To live 10 years in your current health	<input type="checkbox"/>		10.	To live 10 years in your current health	<input type="checkbox"/>

	To live 8 years in full health	<input type="checkbox"/>			To live 2 years in full health	<input type="checkbox"/>
5.	To live 10 years in your current health	<input type="checkbox"/>		11.	To live 10 years in your current health	<input type="checkbox"/>
	To live 7 years in full health	<input type="checkbox"/>			To live 1 year in full health	<input type="checkbox"/>
6.	To live 10 years in your current health	<input type="checkbox"/>		12.	To live 10 years in your current health	<input type="checkbox"/>
	To live 6 years in full health	<input type="checkbox"/>			To live 6 months in full health	<input type="checkbox"/>

If the patient gives an alternative amount of time please write this here:

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Please tick here if the patient did not understand this task:

Thank participant for completing this survey and helping with our research