

# "IT'S HARD TO IMAGINE SITUATIONS THAT YOU'VE NOT EXPERIENCED BEFORE PROPERLY"

Reflections on what aspects of quality of life people value using the Best-Worst Scaling (BWS) task

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October 2016









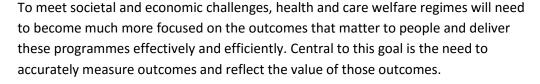


# Disclaimer

This is an independent report commissioned and funded by the NORFACE Welfare State Futures programme under grant number 22119. The views expressed are not necessarily those of the funder.



# Project aim





EXCELC is a cross-country study that has as its core purpose the aim to assess the comparative effectiveness and efficiency of community and home-based long-term care (LTC) for older adults and their informal carers in Austria, England and Finland. EXELC is using the care-related outcome tool, ASCOT, to measure the outcomes of LTC. The study will produce a German (Austrian) and Finnish version of the ASCOT service user and carer instruments.

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ver the summer of 2016, the EXCELC team ran an online survey in Austria, England and Finland to explore the various things that people value in life. Specifically, we wanted to understand people's preferences for different quality of life states described by the ASCOT service user and carer measures. The primary aim of the online survey was to generate country-specific preference weights for the ASCOT service user and carer measures (see ASCOT website <a href="here">here</a>), and secondly to compare people's preferences for quality of life states across the three countries.

There are many methods to draw out people's preferences for quality of life states. We followed a previous ASCOT study and used the 'best-worst scaling' (BWS) method. In BWS tasks people have to trade-off different quality of life states. For our study, we asked participants to trade-off different care-related quality of life states (see example below). The participants' choices reflect the extent to which they value different quality of life situations. We can use this information to put together weights. These weights can then be used to combine responses to multiple questions about different aspects of quality of life into a single score. This score (or index) reflects the *value* of the quality of life state. This score can then be used to compare outcomes from services, for example when conducting an economic evaluation.

#### Best-worst scaling: an example using the ASCOT service user measure

In a best-worst scaling task, people are asked to put themselves in an imaginary situation and consider which items from a set of statements would be the best and worst for them. In this study, we asked people to imagine they were either unable to care for themselves without some assistance (ASCOT service user measure) or were caring for someone who was unable to care for themselves without some assistance (ASCOT carer measure). We presented participants with a list of statements on a screen, with each statement covering a different aspect of quality of life. Participants had to choose which of the quality of life situations they thought was the best and the worst from the list. These first best and worst choices were removed from the list, and participants chose the second best and the second worst situations. This process was repeated a number of times using different lists of statements. The last section examined individuals' understanding and ability to complete the Best-Worst Scaling task.

Best		Worst
0	My home is not quite clean or comfortable enough	0
0	I don't feel at all safe	•
0	I get adequate food and drink at OK times	•
0	I don't feel at all clean or presentable	0
0	I have some control over my daily life, but not enough	•
•	I have adequate social contact with people	•
0	The way I'm helped and treated makes me think and feel better about myself	•
0	I'm able to spend my time as I want, doing things I value or enjoy	•

Figure 1. Example of the BWS task using the wording from the ASCOT service user measure

Both previous research within the field and our past findings suggest that people do not find BWS experiments easy. The presentation of the experiment is therefore important to ensure clarity for those taking part. Arguably this is more important in the online context where there is no interviewer to whom people can ask questions. Before we undertook the online survey, we conducted some cognitive interviews in order to better understand the best way to present the BWS experiment. Cognitive interviews tend to be used in questionnaire development to help test and revise questions or tasks that may not be well understood by participants as intended by the researchers. We asked people to 'think-aloud' while they completed the BWS experiment at the computer so we could capture what they were thinking and feeling and how they were making decisions. After they completed the experiment, we interviewed the participants to probe their understanding of the task and to further examine their decision-making processes.

## How did people find the best-worst scaling task?

Overall we found that people could complete the best worst scaling tasks, but that many of the participants found the tasks challenging. Various aspects of the presentation of the tasks contributed to people's difficulties.

- Imagining yourself as a carer or person needing care. Many participants were able to accept the idea of putting themselves into the imaginary situations. Sometimes participants drew on personal experiences, either their own experiences or their loved ones' experiences. Other participants struggled to imagine needing care or caring for someone. Some also used the preferences they imagined a loved one who needs care would choose. Over the course of the experiment some people also seemed to forget this instruction.
- Understanding how the tasks should be answered. Some participants felt uncertain about whether they were doing the task correctly. Others seemed confused by the terms 'best' and 'worst'. For example, they reflected on whether they were being asked to decide which statement was most 'important' or 'unimportant' and whether this was somehow different to 'best' and 'worst'. We did find, however, evidence of learning. Participants reported finding the task easier and understanding more what they had to do as they progressed through the experiment.
- Repetitive nature of the experiment. The experiment involved answering very similar questions nine times over. Some participants felt frustrated with the similarly-worded and repetitive nature of the task. Some participants even said they would have given up if they were completing it from home.

There were surprisingly similar issues across the three countries. We expected that there would be more context-specific, language-dependent problems but we did not find that to be the case in our current study.

### How we improved the best-worst scaling experiment

To prepare participants better for the task, we revised the presentation of the task in a number of ways.

- Additional information to prepare people for the repetitive nature and ensure completion of the experiment. In the task instructions we set out the number of trials, and emphasised that each trial would show a different list of statements. Following further testing in Finland and Austria, we also added an instruction to clarify that the statements may vary minimally between the tasks. We also added markers (e.g. Task 2 of 8) during the tasks so participants were clear about the length of the task.
- Helping people to put themselves in the imaginary situation throughout the experiment. In the task instructions, we directed participants to pause and visualise the imaginary situation in which they were a carer for someone or needed care, and provided some example to help participants imagine the situation. The Austrian team also restated at the end of the instruction that the participant should take time to think and imagine what life would be like in these imaginary situations. We also integrated the instruction that participants should imagine that they were caring for someone or that they were unable to care for themselves into the question for each BWS task.
- Helping people to understand how to complete the tasks. In the task instructions, we added the terms 'most preferred' and 'least preferred' to help people understand 'best' and 'worst'. We discussed whether or not to also use the term 'importance', but as the Finnish and English studies found, this seemed to be misleading rather than helpful. As a result, this amendment was not included. At the end of each question, we also added 'for you' to make it clear that the participants should think about their own preferences and not the preferences of anyone else. The Finnish team also modified the wording to the question asking people to choose the second best and worst, and instead asked people to choose the worst or best from the reduced list of statements.

In general, what we tried and tested with people in England seemed to apply well to the Finnish and Austrian contexts and required little modification. Only the instruction to choose the second best and second worst option did not seem to translate well to the Austrian and Finnish contexts.

#### **Conclusions**

This study has confirmed that there was a need to test the BWS task in the field before we started the fieldwork for the pilot and main stage of the survey. We found the 'think-aloud' method useful for exploring how people understand the BWS task.

For future research using the BWS method, we recommend that researchers pay particular attention to (i) the clarity of instructions for the BWS task, (ii) the presentation of the questions for each task, (iii) how 'best' and 'worst' can be interpreted, and (iv) preparing people for the repetitive nature of the task. We also suggest that researchers encourage participants time to reflect on what the task is asking them to do and include markers within the task so people can track their progress. These issues do not seem to be country-specific. They are of general relevance.

This study also suggests a range of interesting directions for future research around optimising the presentation of BWS experiments. The frustration people expressed around repetitiveness raises a number of questions. For example, how many is the optimal number of tasks to present to someone? Should tasks be presented in an order that maximises the differences between the two tasks? Is randomisation of the ordering of tasks a good idea?