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Linnosmaa, Ismo, Trukeschitz, Birgit, Kruese, Tobias, Hajji, Assma, Haula, Taru, Nguyen, Lien, Malley, Juliette, Razik, Kamilla and Forder, Julien E. (2016) *Translation and cross-cultural validation of ASCOT instruments into German and Finnish*. In: 4th International Conference on Evidence-based Policy in long-term care, 4-7 September 2016, London. (Unpublished)

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EXCELC
Exploring Comparative
Effectiveness and Efficiency
in Long-term Care

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Translation and cross-cultural validation of ASCOT instruments into German and Finnish

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Outline

- I. Background and objectives
- II. ASCOT
- III. Translating ASCOT
- IV. Cognitive interviews
- V. Main findings
- VI. Conclusions

I Background and objectives

- Cross-cultural use of outcome measures has become common
- Need to establish cross-cultural equivalence and face validity of the translated instruments
- ASCOT tools were translated into Finnish and German → EXCELC research project
- Our objective is to evaluate the cross-cultural validity and equivalence of the translated instruments

II The outcome measure

- **ASCOT – Adult Social Care Outcomes Toolkit**
- Developed at University of Kent, England
- The instrument can be used to measure
 - ✓ Social care related quality of life SCRQoL
 - ✓ Effectiveness of adult social care services
- Effectiveness of services = QoL with services – QoL without services

ASCOT
adult social care outcomes toolkit

<http://www.pssru.ac.uk/ascot/>

II ASCOT domains

ASCOT (for service users) has 8 domains

- ✓ Control over daily life
- ✓ Personal cleanliness and comfort
- ✓ Food and drink
- ✓ Personal safety
- ✓ Social participation and involvement
- ✓ Occupation
- ✓ Accommodation cleanliness and comfort
- ✓ Dignity

III Translating/adaptating ASCOT

- Our translation work
 - ✓ started in June 2015 and was completed in March 2016
 - ✓ was carried out by translating agency PharmaQuest (now part of Corporate Translations) in cooperation with research teams from Austria and Finland (also England)
- ASCOT instruments
 - ✓ SCT4 Service Users and Carers
 - ✓ INT4 Service Users and Carers
- were translated into Finnish and German
- as part of the international research project

**Exploring Comparative Effectiveness and Efficiency in Long-term Care
(EXCELC, www.excelc.eu.org)**

III Stages of translations/adaptations

- ✓ Concept elaboration
 - ✓ Conceptual meaning of the instrument (June-July 2015)
- ✓ Two forward translations from English into both German and Finnish (4 translations in total)
- ✓ Reconciliation of the two translations into a single culturally relevant and linguistically correct translation
- ✓ Back translations from German and Finnish into English
- ✓ Back translation review
 - ✓ Review of the back translation with the source versions
 - ✓ Resolution of discrepancies, if any
- ✓ Developer review



III Stages of translations/adaptations

- ✓ Independent proofreading
- ✓ Client affiliate review
 - ✓ Comments from researchers
- ✓ Professional review
 - ✓ Comments from social workers in Austria and Finland
- ✓ Pilot testing and **cognitive interviews**
 - ✓ To establish cross-cultural equivalence
- ✓ Pilot testing review
- ✓ Investigator proofreading
- ✓ Final report (March 2016 – 1,542 pages)

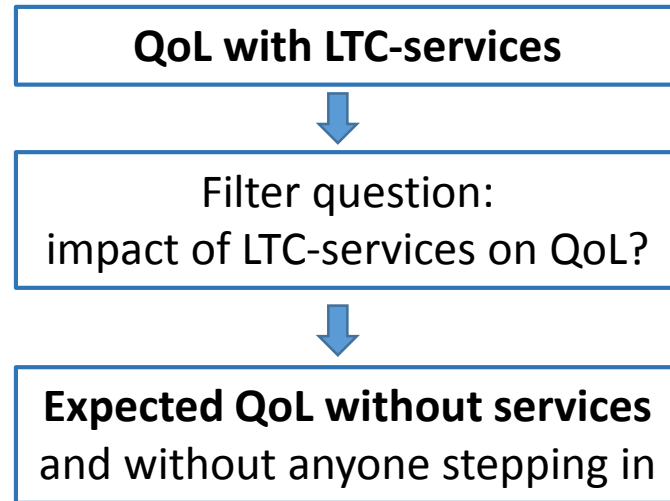


IV Cognitive interviews

- Cognitive interviews (CIs) to establish cross-cultural equivalence of the translated questionnaires (Willis, 2005)
- CIs were carried out in January-February 2016 in Finland and November-December 2015 in Austria
- We interviewed
 - ✓ 5 family carers in each country
 - ✓ 5 service users in each country
- Respondents ...
 - Finland: ...were recruited by City of Helsinki social services
 - Austria: ... were clients of 2 major LTC service providers in Vienna
- Interviewers were native Finnish and Austrian speakers
- The think-aloud method with flexible probing was applied (Willis, 2005):
 - ✓ Do you understand?; Are options appropriate?; Explain in your own words the meaning of the sentence; comments



Main findings: the logic of ASCOT



CIs: **responses to filter question and expected QoL did not always match** → leave filter question but do not use filter, explore response patters in the main stage fieldwork



CIs: some respondent tended to **provide an answer rather than to paraphrase** this question; high care dependencies: difficulties to imagine the situation without help (“catastrophe”, not possible without care home)

CIs-Carers: **imagined themselves or family members stepping in** → slightly rephrased, emphasis on no one stepping in



CIs: The Finnish translation “eikä muutakaan apua olisi saatavilla” refers to situation with no help at all. This **may bias the self-evaluation of the counterfactual situation**. → We **changed the sentence**: Imagine that you didn't have the support and services from <<EXAMPLE>> that you do now and no other help compensating the support and services stepped in.

V Main findings:

Differences in LTC systems and its implications for the questionnaire



ASCOT interviewer prompt	CONFUSION/MISUNDERSTANDING	RESPONSE Finland
Please do not include help from health professionals such as GPs and nurses, or from friends and family. (Instruction when evaluating the effects of formal services)	Family carers are very often spouses or other members of the family. By excluding friends and family, one often excludes family carers. And family carers (contracting with municipalities) in Finland are part of the formal care under evaluation.	We changed the interviewer prompt: Please do not include help from health professionals such as GPs and nurses, or from friends and family that is not part of the formal family care system.

V Main findings:

Differences in language complexity and its implications for the length of sentences: e.g. food and drink



3. Thinking about the food and drink you get, which of the following statements best describes your situation?

Please tick (☑) one box

- | | | |
|--------------------------|--|----------------------------|
| <input type="checkbox"/> | I get all the food and drink I like when I want | <input type="checkbox"/> |
| ➔ | I get adequate food and drink at OK times | ← <input type="checkbox"/> |
| <input type="checkbox"/> | I don't always get adequate or timely food and drink | <input type="checkbox"/> |
| <input type="checkbox"/> | I don't always get adequate or timely food and drink, and I think there is a risk to my health | <input type="checkbox"/> |



3. Welche der folgenden Aussagen beschreibt am besten Ihre derzeitige Situation, wenn Sie daran denken, was Sie zu essen und zu trinken bekommen?

Bitte kreuzen Sie ein Kästchen an (☑).

- | | | |
|--------------------------|---|----------------------------|
| <input type="checkbox"/> | Ich bekomme alles zu essen und zu trinken, was ich möchte und wann ich möchte. | <input type="checkbox"/> |
| ➔ | Ich bekomme zu mir angenehmen Zeiten ausreichend und angemessen zu essen und zu trinken. | ← <input type="checkbox"/> |
| <input type="checkbox"/> | Ich bekomme nicht immer zu mir angenehmen Zeiten ausreichend oder angemessen zu essen und zu trinken. | <input type="checkbox"/> |
| <input type="checkbox"/> | Ich bekomme nicht immer zu mir angenehmen Zeiten ausreichend oder angemessen zu essen und zu trinken und ich glaube, dass das meine Gesundheit gefährdet. | <input type="checkbox"/> |

Interestingly, response options are long but did not turn out to be too difficult.

V Main findings:
Wording: e.g. "adequate"



ASCOT wording	CONFUSION/MISUNDERSTANDING	OUR RESPONSE
I have adequate control over my daily life.	Respondents asked who defines what is "adequate". They thought that adequate is defined by an outside assessment e.g. by doctors or social workers.	We changed the interviewer prompt: Please answer the question on the basis of your current situation and personal experience.



I get adequate food and drink at OK times .	The term "adequate" is well-known but not commonly used in this context in German	We specified the meaning of adequate to assure that everyone understands it in the same way. "enough and appropriate food and drink"
		"adequate" in other domains was translated as enough/sufficient

V Main findings:

Wording of response options: Social participation and involvement

5. Thinking about how much contact you have with people you like, which of the following statements best describes your social situation?

Please tick (☑) one box

I have as much social contact as I want with people I like	<input type="checkbox"/>
I have adequate social contact with people	<input type="checkbox"/>
I have some social contact with people, but not enough	<input type="checkbox"/>
I have little social contact with people and feel socially isolated	<input type="checkbox"/>



CONFUSION/MISUNDERSTANDING

CIs: The question and the first response option refer explicitly to the “people you like” but the last three response options refer to social contacts with all people and not just people you like. Some found this confusing because the response options makes you think about different kinds of social contacts.

OUR RESPONSE

We did not change this!



CIs: No problems to distinguish response options. However, in a survey on the effectiveness of AAL-solutions some people ticked the first two options and explained that both apply.

We did not change this!

V Main findings: Wording: Control over daily life

1. Which of the following statements best describes how much control you have over your daily life?

By 'control over daily life' we mean having the choice to do things or have things done for you as you like and when you want.

Please tick (☑) one box

I have as much control over my daily life as I want	<input type="checkbox"/>
I have adequate control over my daily life	<input type="checkbox"/>
I have some control over my daily life, but not enough	<input type="checkbox"/>
I have no control over my daily life	<input type="checkbox"/>



“Control over daily life” was difficult to translate as a literal translation is not common in the German language of everyday life. It would sound too strict and would thus not capture the meaning properly.

A different wording was chosen which translates the phrase into being able to influence daily life

V Main findings: cultural differences how people talk about their feelings

8. Which of these statements best describes how having help to do things makes you think and feel about yourself?

Please tick (☑) one box

Having help makes me think and feel better about myself	<input type="checkbox"/>
Having help does not affect the way I think or feel about myself	<input type="checkbox"/>
Having help sometimes undermines the way I think and feel about myself	<input type="checkbox"/>
Having help completely undermines the way I think and feel about myself	<input type="checkbox"/>



CONFUSION/MISUNDERSTANDING

CIs: Some respondents felt that the Finnish-translated sentence is too complicated because it makes you think about your thoughts and feelings. However, many also thought that the phrasing is justified. All respondents agreed that replacing the word “vastaanottajana” by the word “saajana” improves the sentence.

OUR RESPONSE

We replaced the word “vastaanottajana” (receiver) by the word “saajana” (recipient).



CIs: to “think and feel about oneself” could not be translated literally as people did not like to talk in this way about themselves.

Changed wording to: how having help affects your self-esteem

VI Conclusions

- CIs gave a feeling/understanding how service users and carers understand the phrasing and questions in the questionnaires
- We came across issues at different layers:
 - (i) the logic of ASCOT (potential simplification of the tool and cross-cultural differences in imagining the hypothetical situation)
 - (ii) differences in the LTC systems and their implications for the wording
 - (iii) difficulties in translating terms (“adequate”) and phrases/concepts (“control over daily life”) into German/Finnish
 - (iv) cross-cultural differences in how people talk about their feelings
- In general, CIs in Finland and Austria were useful and pointed to phrasing and wording in the translated questionnaires that were understood differently from the original wording and phrasing
- CIs are recommended to be used when translating outcome measures

Disclaimer

This is an independent report commissioned and funded by the NORFACE Welfare State Futures programme under grant number 22119 and by the Austrian Science Fund (FWF). The views expressed are not necessarily those of the funders.

PSSRU
University of Kent



V Sample for cognitive testing

Service Users

Participant Number	Age	Gender	Amount of years receiving social care
R1	65	female	17 (carer allowance since the year 1999)
R2	73	male	4
R3	74	female	12 (carer allowance since the year 2004)
R4	79	male	14 (carer allowance since the year 2002)
R5	73	female	3 (carer allowance since the year 2013)

Carers

Participant Number	Age	Gender	Amount of Years as a Carer
1	67	male	11 (carer allowance since 2005)
2	75	female	4 (carer allowance since 2011)
3	78	male	12 (carer allowance since 2004)
4	65	female	14 (carer allowance since 2002)
5	73	male	3 (carer allowance since 2013)



ASCOT INT4 & SCT4 Service Users – Pilot Testing Demographic Form

V Sample for cognitive testing

Service Users

Participant Number	Age	Gender
R1	55	male
R2	76	male
R3	59	female
R4	81	male
R5	85	male

Carers

Participant Number	Age	Gender
R1	46	female
R2	45	female
R3	41	female
R4	64	female
R5	73	female



ASCOT INT4 & SCT4 Service Users – Pilot Testing Demographic Form