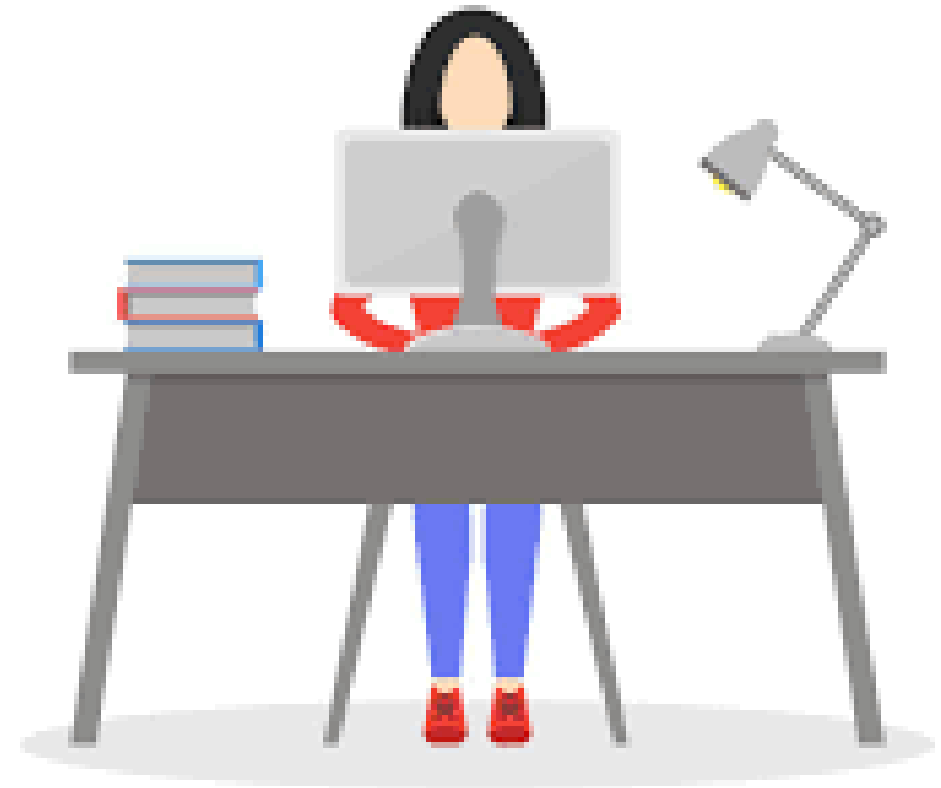


Enhancing our understanding of measuring quality of life of people with dementia who are unable to self-report



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Disclaimer

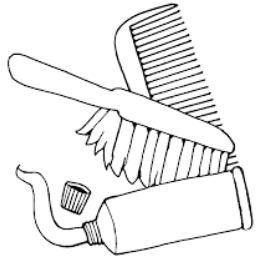
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- The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

Background – ASCOT Proxy

- To work around this, an adapted version of the Adult Social Care Outcomes Toolkit (ASCOT)* questionnaire, ASCOT-Proxy, has been developed.
- *The ASCOT questionnaires are used to collect information on the quality of life of people who use social care services and their carers.



Background – ASCOT Proxy



Personal cleanliness
and comfort



Food and drink



Safety



Clean and comfortable
accommodation



Social participation
and involvement



Control over daily living



Occupation



Dignity

23. Thinking about the food and drink the person you represent gets, which of the following statements best describes his/her situation?

Please say ***what you think*** in the first column. Then say ***how you think the person you are representing would answer*** in the second column. Please write in the comments box if you wish to add anything to your answer.

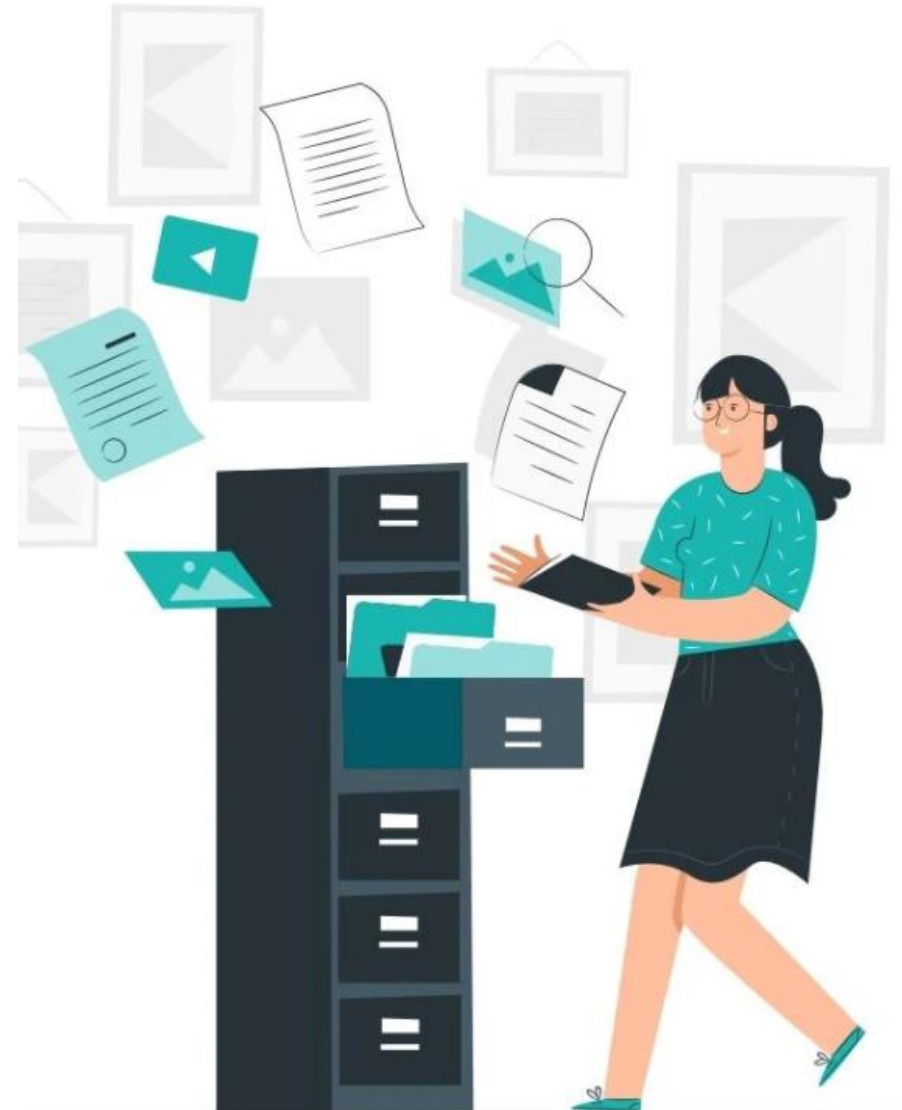
The person I am representing...

Please tick (✓) one box for each column

	My opinion (What I think)	What I think the person I represent thinks	
Gets all the food and drink s/he likes when s/he wants	<input type="checkbox"/>	<input type="checkbox"/>	Ideal state
Gets adequate food and drink at OK times	<input type="checkbox"/>	<input type="checkbox"/>	No needs
Doesn't always get adequate or timely food and drink	<input type="checkbox"/>	<input type="checkbox"/>	Some needs
Doesn't always get adequate or timely food and drink, and there is a risk to his/her health	<input type="checkbox"/>	<input type="checkbox"/>	High needs

The Aim

- To understand whether ASCOT-Proxy is easy to complete and measure what it is intended to measure – that is, social care-related quality of life (SCRQoL)



Participants – MOPED study

Carers: 62.4 years (SD:12.0); 75.7% (n=237) females; 94.6 % (n=296) White/White British; 47% (n=147) provided 50+hours per week of care; 14% (n=268) provided ≥ 10 years of care

People with dementia: 81.5 years (SD: 9.4); 90.4% (n=283) were partners/spouses/parents; 57.8% (n=181) lived in the same household

Survey mode	Recruitment		Total
	JDR	NHS	
Postal	8	55	63
Online (Qualtrics)	165	85	250
Total	173	140	313

Inclusion criteria:

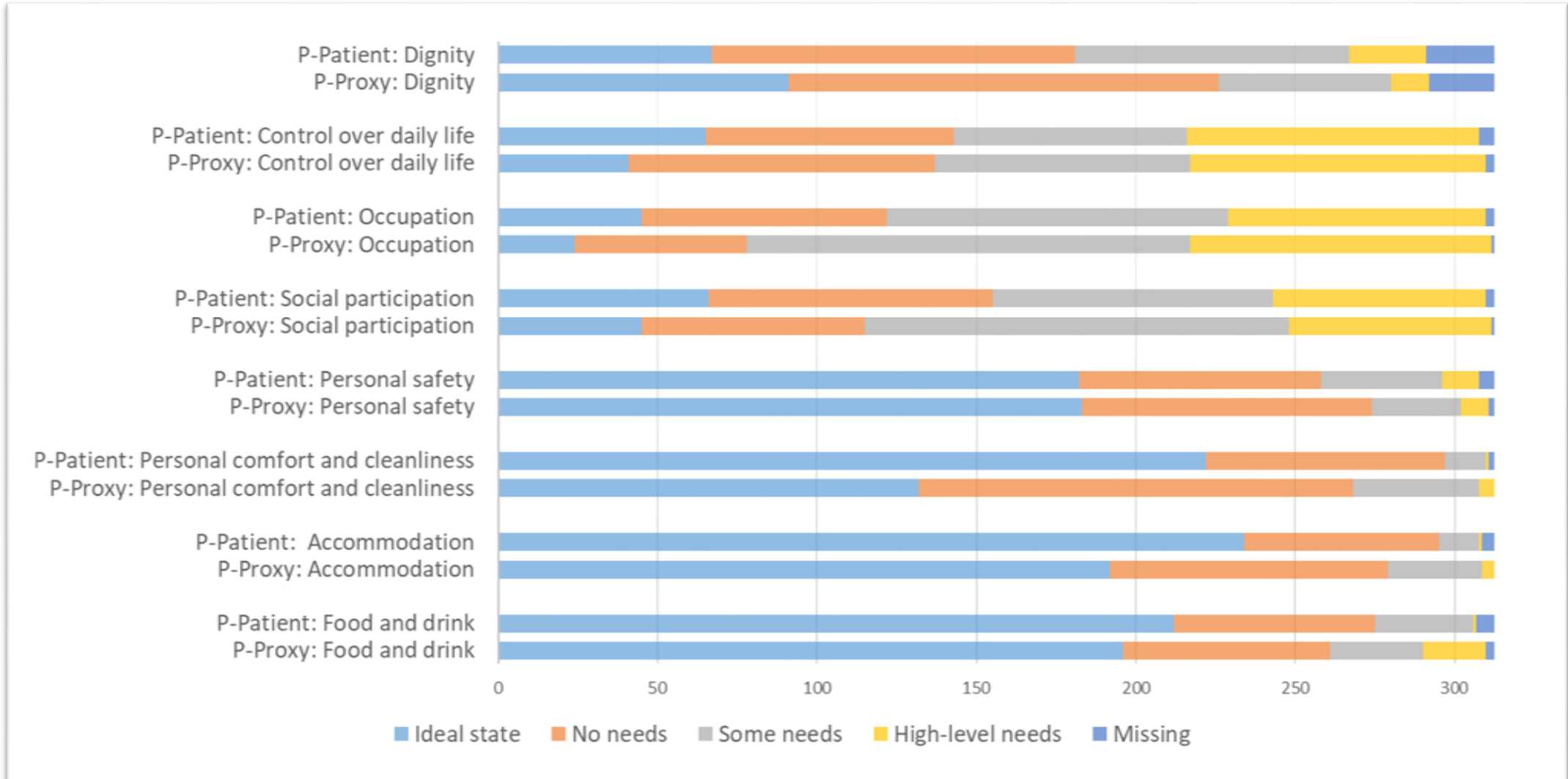
A friend or family member of someone living with dementia, who:

- Lives at home (not in a nursing or residential care home)
- Uses at least one type of social care service
- Would not be able to answer a postal or online questionnaire, even with help.

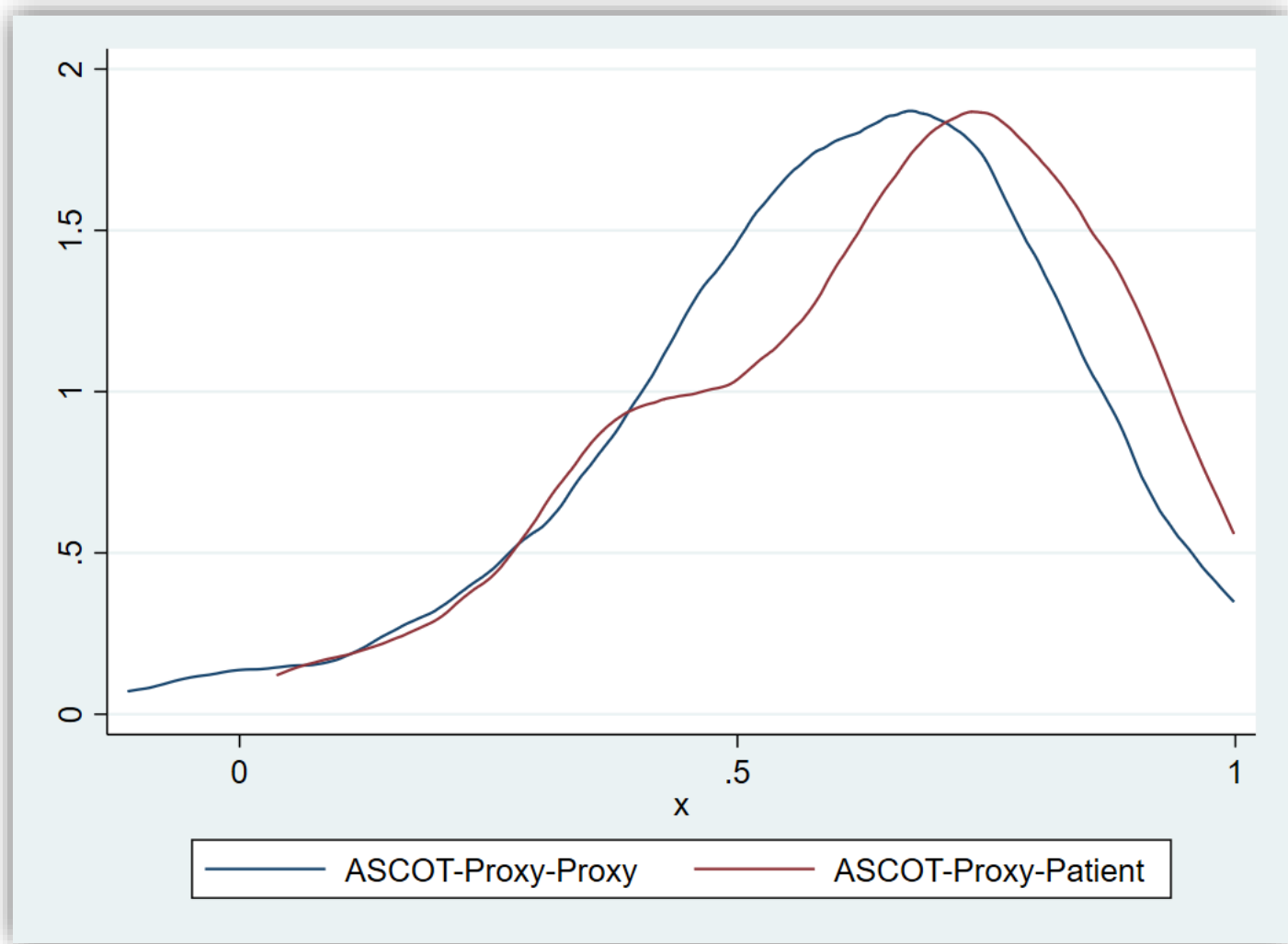


Results

Distribution of responses - ASCOT-Proxy



Distribution of responses - ASCOT-Proxy



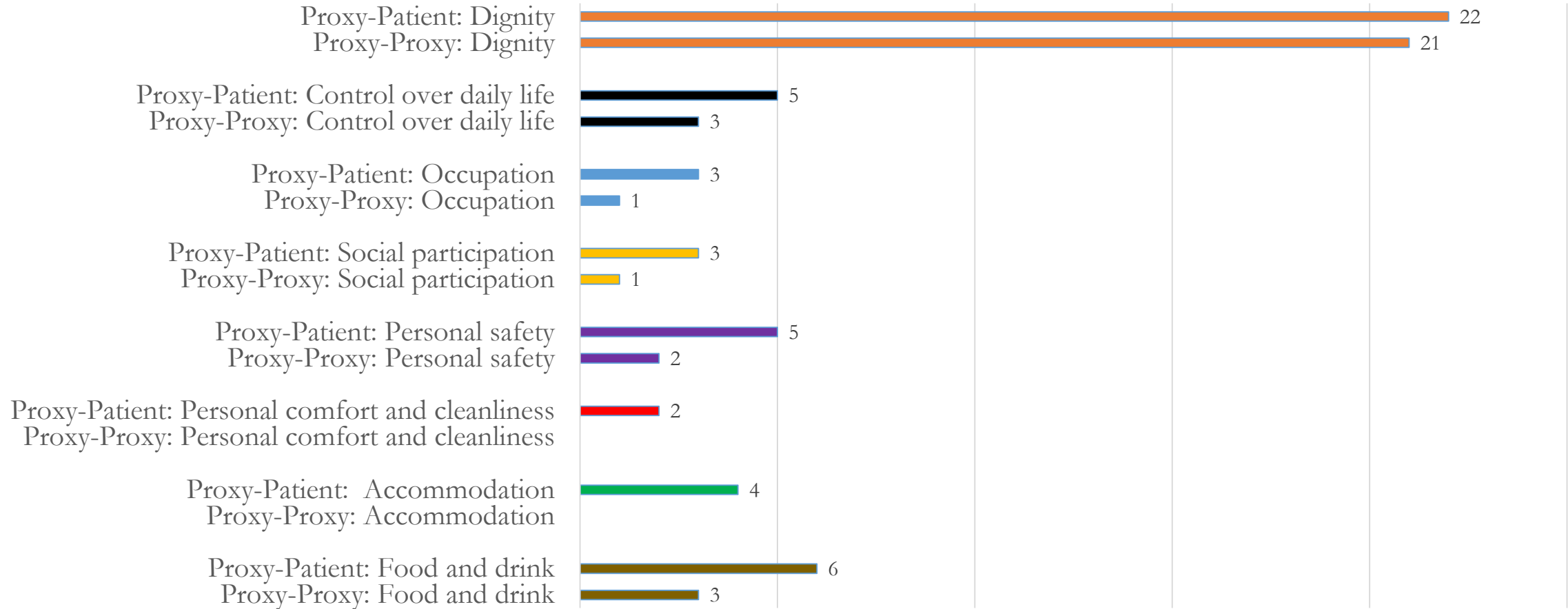
Variable	N	Mean	SD
P-Proxy	275	.597	.219
P-Patient	275	.642	.218
Difference	275	-.046	.220
$\Pr(T > t) = 0.0006$			

Correlation between Proxy-Proxy and Proxy-Patient

Spearman's rho = 0.54 (moderate correlation)

Feasibility (acceptability) - ASCOT-Proxy

Missing values: n out of 313



Internal consistency (reliability) - ASCOT-Proxy

Proxy-Proxy

- Number of items in the scale: 8
- Scale reliability coefficient: 0.68

Proxy-Patient

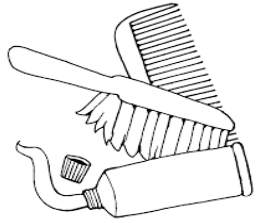
- Number of items in the scale: 8
- Scale reliability coefficient: 0.69

Cronbach's alpha (a coefficient of reliability) > 0.6 is considered acceptable

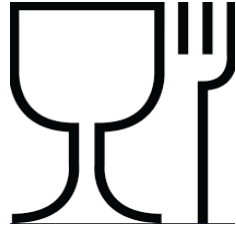
Construct validity - ASCOT-Proxy

Measures of related constructs	Proxy-Proxy		Proxy-Patient	
	Spearman's rho		Spearman's rho	
Health-related quality of life				
EQ-5D-Proxy-Proxy	0.3	weak	0.4	moderate
EQ-5D-Proxy-Patient	0.2	weak	0.4	moderate
Proxy-rated condition-specific quality of life				
DEMQOL	0.2	weak	0.4	moderate
Overall quality of life				
Proxy-Proxy	0.5	moderate	0.4	moderate
Proxy-Patient	0.3	weak	0.6	moderate

Structural validity - ASCOT Proxy



Personal cleanliness
and comfort



Food and drink



Safety



Clean and comfortable
accommodation



Factor 1
Basic needs



Social participation
and involvement



Control over daily living



Occupation



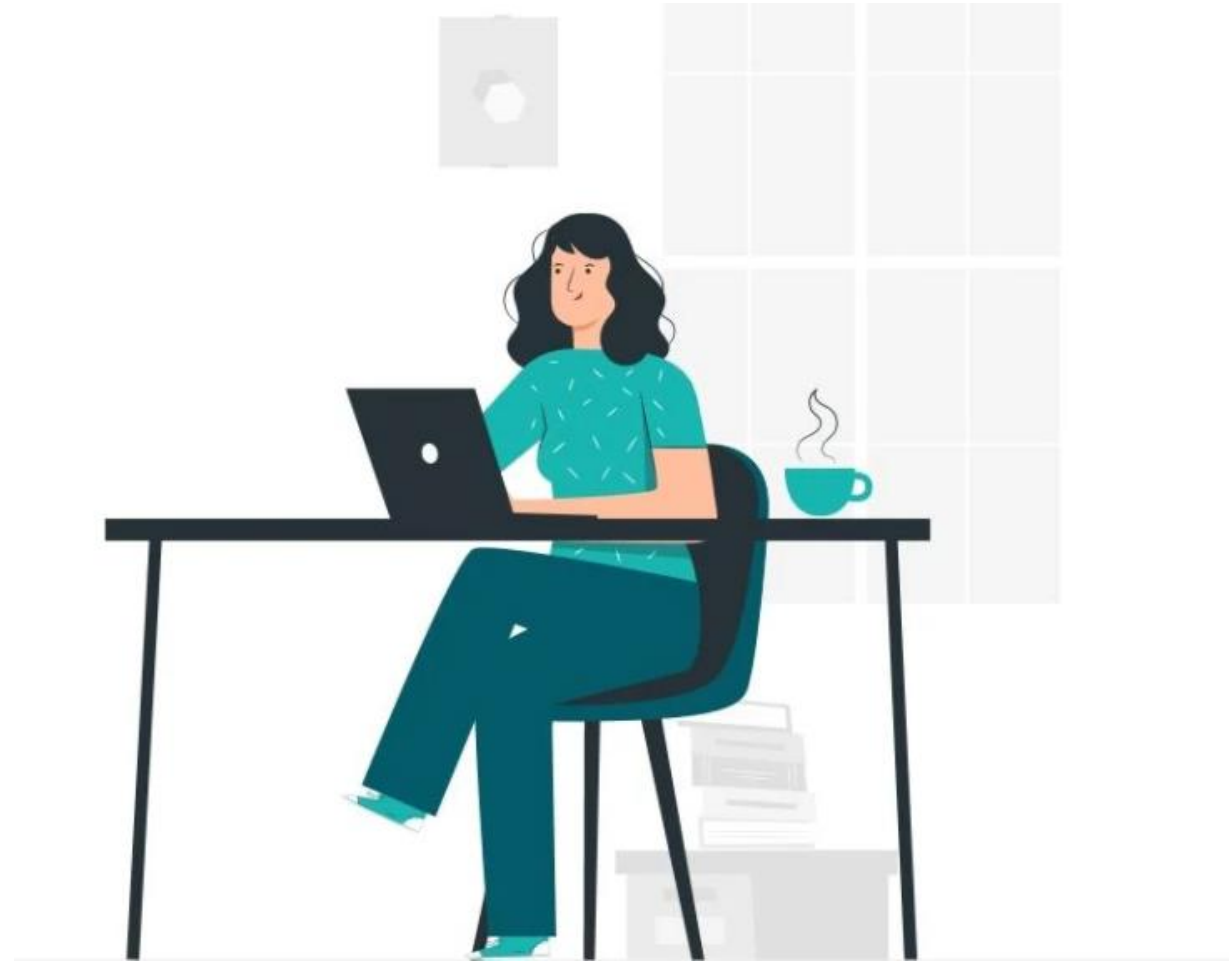
Factor 2
Higher order needs



Dignity

Summary - ASCOT-Proxy

- ASCOT-Proxy is a feasible, valid and reliable measure of social care-related quality of life.
- There is a difference between proxy report perspectives.
- Further analysis of ASCOT-Proxy are needed (construct and structural validity).
- Role of mode of administration (online vs postal).



Our Team

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Thanks for your attention!

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