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Original research

EORTC QLQ-C30 normative data for the United Kingdom: Results of a cross-sectional survey of the general population

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ABSTRACT

Objective: The cancer-specific health-related quality of life (HRQoL) questionnaire of the European Organisation for Research and Treatment of Cancer (EORTC), the EORTC QLQ-C30, is a frequently applied questionnaire to assess cancer patients' self-reported health used as part of research and clinical practice. Normative data obtained from the general population can facilitate the interpretation of these data. Despite its frequent application, no detailed EORTC QLQ-C30 normative data have yet been published for the United Kingdom (UK). This study presents detailed EORTC QLQ-C30 normative data for the United Kingdom overall and by sex and age.

Methods: The data are drawn from a larger published, international, cross-sectional online survey. For the recruitment, the sample was stratified by sex (males, females) and age in five age groups with a sample size of n = 100 per subgroup.

Results: A total of N = 1026 UK respondents completed the survey (n = 517 females, n = 509 males). There were no clear subgroup patterns by sex or age; however, older patients tended to show higher (i.e., better) scores in emotional and social functioning; they also reported some of the lowest (i.e., best) scores for symptoms, such as insomnia, appetite loss, diarrhoea, nausea/vomiting or financial difficulties.

Conclusion: This paper provides EORTC QLQ-C30 general population normative data for the UK, further stratified by sex and age. These data will greatly support the interpretation of EORTC QLQ-C30 scale scores obtained from UK cancer patients, and also enable comparison with other detailed national normative datasets collected in the same project, across several other European countries and the US.

1. Introduction

Traditionally, cancer studies of new treatments have been evaluating clinical outcomes, such as remission or survival rates, to help clinicians decide the optimal treatment for their patients. However, since the 1980s the importance of adding patient-reported outcomes (PROs) to clinical trials has been increasingly recognised [1]. PROs add a patient's perspective to the more readily available clinical information [2] and can be taken into consideration, for example, by regulatory decision makers [3,4]. There are also institutions where, following clinical trials, PROs have been introduced into routine clinical care for health care teams to develop clinical and supportive care plans for their patients [5–7]. Whatever the context, it is always helpful to have some guidance or comparison to aid interpretation of the results and scores that are presented.

There are several published methodologies for interpreting PROs,

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both at an individual patient level and at the group level [8,9]. The EORTC QLQ-C30 is a widely used PRO for cancer patients and projects have been undertaken to support interpretation of EORTC QLQ-C30 results. Where consecutive measurements are available, researchers have determined the minimum score change necessary for patients to notice a difference that is meaningful to them. The term minimal important change (MIC) is used for interpretation of scores at the individual patient level [10] whilst minimal important differences (MID) is used for group level scores [11]. When only a single measure at one time point is available, researchers have determined thresholds for clinical importance. Dependent upon scale direction, scores above or below the threshold indicate that the functioning or symptom is clinically important and should be investigated further with the possibility of offering an intervention [12]. Other options for interpreting PRO data involve comparison of patients' scores with reference data collected from similar cancer patients [13] or with normative data collected from the general population. Using normative data, possible comparisons could include mean scores (with and without adjustments for age/sex) or looking at score distributions, e.g., the proportion of patients whose scores fall below the 10th percentile score from the normative population. Until recently, normative datasets have only been collected in national projects as summarised by Hinz et al. (2014) [14]. A recent study supported by the EORTC Quality of Life Group (QLG) (the developers of the EORTC QLQ-C30) collected normative data from over 15,000 people across 15 countries, including the UK [15]. This paper reports results from 1026 participants from the UK that were derived from that larger, multi-national dataset.

2. Methods

2.1. EORTC QLQ-C30

The EORTC QLQ-C30 contains 30 questions with five functioning scales (Physical, Role, Emotional, Cognitive, Social) and eight symptom scales/items (Fatigue, Nausea/vomiting, Pain, Dyspnoea, Insomnia, Appetite loss, Constipation and Diarrhoea) plus a financial difficulties scale and a global health status/Quality of Life (QoL) scale [16]. Except for the Physical Functioning scale that does not have a recall period, respondents are asked to recall the previous week and respond on a four-point Likert scale from 'Not at all' (1) through 'A little' and 'Quite a bit' to 'Very much' (4). For each scale, summed scores are linearly converted to a 0–100 scale [17]. For the functioning scales, higher scores indicate good functioning, whilst for symptoms high scores indicate more symptom burden.

2.2. Sample

This QLG funded project aimed to define the European norm for the EORTC QLQ-C30. The project team subcontracted the panel research company GfK to collect representative data from about 1000 persons per country, with 11 EU countries plus Russia, Turkey, US and Canada: the latter four included for comparative purposes. Data collection took place between March-April 2017. Quota sampling was applied to obtain n = 100 participants per pre-specified subgroup defined by age (five age categories: 18–39, 40–49, 50–59, 60–69, 70+ years) and sex (male/female). A quota sampling was chosen to ensure a sufficiently large sample size in each subgroup to enable age-/sex-specific comparisons when interpreting an individual cancer patient's score. Whilst the youngest and the oldest age groups are larger than the remaining three age groups, age bands were chosen pragmatically as part of the original multi-national study [15]. First, the focus was on the older age groups to reflect cancer prevalence. Second, whilst we would have preferred to divide the oldest age group into 70–79 years and 80+ years, we were limited by budgetary constraints as older age groups are harder and more costly to recruit. In view of response rate, GfK claims to reach response rates of 75%– 90% as panel members are registered voluntarily, and it is expected that they participate when invited. Of note, participants are required to have internet access to be able to take part in these types of surveys. Sociodemographic data was also collected, alongside data on current health conditions. Full details of the original study and sampling are provided by Nolte et al. (2019) [15].

2.3. Statistical analysis

Since the general population norm data was collected based on equal sample sizes per age/sex stratum, it was necessary to weight the data when calculating normative data for the overall sample. Weighting was carried out according to the UK population age/sex distribution statistics, with weights derived from 2015 figures published by the United Nations, Department of Economic and Social Affairs, Population Division [18]. Frequency counts were used to describe the sociodemographic and health data of the participants. Mean functioning and symptom scale scores from the EORTC QLQ-C30 were calculated and weights used when presenting the whole-sample. Subgroup analyses were undertaken by age group, by sex and age/sex together. We chose to use a cut-off of > 10 [19] to identify clinically meaningful differences between participant groups, in line with similar linked publications on other national datasets from Austria, Germany and the Netherlands [20–22]. Data was analysed using IBM SPSS version 22.

3. Results

3.1. Sample characteristics

The total UK sample was N = 1026, with 100 + participants in each age/sex subgroup except males in age group 40–49 years (n = 98). Table 1 shows the sociodemographic data for all respondents, both unweighted and weighted. Mean age was 53.5 years; almost two thirds were in a steady relationship. One third had a university degree, i.e., Bachelor's degree or above. Only 7.4% of the sample were non-white. The most common employment status was retired (32.2%) or full-time employment (30.0%); 62.8% of respondents self-reported an existing health condition, the most common being chronic pain (20.8%).

3.2. Normative Data for the general UK population

Unweighted and weighted EORTC QLQ-C30 mean scores and standard deviations are shown in Table 2. The lowest functioning score (weighted) is for emotional functioning (71.0); other functioning scales are higher, ranging from 80.2 to 81.8. Fatigue, insomnia and pain are the most frequently reported symptoms at 32.2, 32.6 and 26.7 respectively. Differences between weighted and unweighted mean scores are small ranging from − 0.1 (role functioning) to + /− 1.9 (emotional functioning and appetite loss) suggesting the weighting procedure has little impact on the normative mean scores.

3.3. HRQoL by sex

Table 3 shows weighted and unweighted EORTC QLQ-C30 scales by sex.

Overall, few group differences were seen between males and females - the only difference approaching a clinically meaningful difference was insomnia (males 28.3 vs. females 36.7).

3.4. HRQoL by age

Table 4 shows EORTC QLQ-C30 scales by age groups in 10-year intervals, except for the first group, which is 18–39 years. For all but physical functioning, the highest (best) functioning is always seen in the oldest age group. For emotional, cognitive and social functioning an almost monotonic increase in scores is seen with age. For role functioning and global QoL the poorest functioning is seen in 50–59 age

Table 1
Sociodemographic Data – All participants (N = 1026), unweighted and weighted.

	Unweighted		Weighted	
	Count	%	Count	%
Mean age (SD)	53.5 (15.5)		47.0 (17.5)	
(Range)	(18–86)		(18–86)	
Sex				
Male	509	49.6%	502	48.9%
Female	517	50.4%	524	51.1%
Age (years in categories)				
18-39	209	20.4%	400	39.0%
40-49	199	19.4%	170	16.5%
50-59	207	20.2%	164	16.0%
60-69	208	20.3%	137	13.3%
70 +	203	19.8%	156	15.2%
Education				
Less than compulsory education	15	1.5%	15	1.5%
Compulsory (left school at the minimum school leaving age)	265	25.8%	237	23.4%
Some post-compulsory (some school after reaching school leaving age without reaching university entrance qualifications	186	18.1%	188	18.5%
Post compulsory below university (e.g., reaching A levels)	210	20.5%	220	21.7%
University degree (Bachelor's or equivalent level)	275	26.8%	282	27.8%
Postgraduate degree (Master's, Doctorate or equivalent level)	65	6.3%	72	7.1%
Preferred not to answer	10	1.0%		
Employment Status				
Employed full-time	308	30.0%	361	35.3%
Employed part-time	102	9.9%	105	10.3%
Homemaker	90	8.5%	96	9.4%
Student	18	1.8%	43	4.2%
Unemployed	80	7.8%	89	8.7%
Retired	330	32.2%	242	23.6%
Self-employed	66	6.4%	64	6.3%
Other (please specify)	29	3.1%	24	2.3%
Preferred not to answer	3	0.3%		
Relationship Status				
Single / not in a steady relationship	206	20.1%	255	24.9%
Married or in a steady relationship	659	64.2%	644	63.1%
Separated / divorced / widowed	156	15.2%	123	12.0%
Preferred not to answer	5	0.5%		
Ethnicity				
White	950	92.6%	916	89.2%
Asian	36	3.6%	60	6.0%
Black	16	1.6%	22	2.2%
Mixed	12	1.2%	17	1.7%
Other	8	0.8%	17	1.7%
Preferred not to answer	4	0.4%		
Health Status				
No health conditions/disease	349	34.0%	399	40.5%
At least one health condition	644	62.8%		
Preferred not to answer	33	3.2%		
Chronic pain (for example, low back pain, neck pain)	213	20.8%	193	19.6%
Heart disease (for example, coronary heart disease, heart attack, heart failure)	65	6.3%	57	5.8%
Cancer (excluding basal cell carcinoma)	33	3.2%	28	2.9%
Depression	167	16.3%	173	17.5%
Chronic Obstructive Pulmonary Disease (COPD)	42	4.1%	35	3.5%
Arthritis (for example, osteoarthritis, rheumatoid arthritis)	195	19.0%	151	15.3%
Diabetes	106	10.3%	86	8.7%
Asthma	102	9.9%	99	10.1%
Anxiety disorder	116	11.3%	125	12.7%
Obesity	69	6.7%	66	6.6%
Drug/alcohol use disorder	19	1.9%	22	2.2%
Other	158	15.4%	137	13.9%

SD = standard deviation

Table 2
EORTC QLQ-C30 general population normative data for adults in the UK. Mean scores and standard deviations for functioning and symptom scales unweighted and weighted.

	Unweighted		Weighted		Mean difference
	Mean	(SD)	Mean	(SD)	
Functioning Scales					
Physical Functioning	81.2	(23.5)	81.8	(23.5)	-0.6
Role Functioning	80.1	(29.4)	80.2	(29.1)	-0.1
Emotional Functioning	72.9	(27.5)	71.0	(28.4)	1.9
Cognitive Functioning	81.7	(23.8)	80.5	(25.2)	1.2
Social Functioning	81.4	(28.7)	80.3	(29.4)	1.1
Global health status/QoL	62.0	(23.8)	62.3	(23.7)	-0.3
Symptom Scales					
Fatigue	31.4	(27.7)	32.2	(27.7)	-0.8
Nausea and vomiting	6.4	(16.4)	8.1	(18.9)	-1.7
Pain	27.2	(31.4)	26.7	(31.2)	0.5
Dyspnoea	19.1	(27.5)	19.5	(27.9)	-0.4
Insomnia	33.4	(32.9)	32.6	(32.8)	0.8
Appetite loss	12.3	(23.6)	14.2	(25.2)	-1.9
Constipation	13.4	(24.8)	14.7	(26.2)	-1.3
Diarrhoea	9.7	(21.1)	11.2	(23.0)	-1.5
Financial difficulties	13.0	(27.4)	14.5	(28.7)	-1.5

SD = standard deviation; QoL = Quality of Life

category. The largest range suggesting clinically meaningful group differences is seen for emotional (17.1) and social functioning (10.8), and the smallest for physical functioning (4.3). The worst symptom levels are associated with the younger and middle age groups, particularly age group 50–59 years. Only physical functioning and dyspnoea have a range of less than 5 points across all the age groups.

3.5. HRQoL by age and sex

Table 5a 5b and Fig. 1a and 1b show data by sex and age. Clinically meaningful age-group differences within males are seen in emotional, cognitive and social functioning, global QoL, nausea/vomiting, pain, insomnia, appetite loss, diarrhoea and financial difficulties, with the largest group differences observed in emotional functioning and financial difficulty. For functioning, except for physical functioning, the oldest males (70+ years) regularly show the highest/best scores, especially when compared to the three youngest age groups. For symptoms, results are mixed, but the youngest males tended to show higher symptom burden, especially when compared with the two oldest age groups which was especially true for nausea/vomiting, appetite loss, diarrhoea and financial difficulties.

For females, clinically meaningful age-group differences are seen in emotional and social functioning, global health status/QoL, fatigue, appetite loss and financial difficulty, with the largest group differences again observed in emotional functioning and financial difficulty. Overall, with the exception of physical functioning, the two oldest age groups tended to show higher functioning compared with the three youngest age groups. For symptoms, similar to the findings for males, the results are more mixed, but the three youngest age groups showed some higher symptom burden, especially when compared with the two oldest age groups, e.g., in fatigue, appetite loss and financial difficulty.

Most of the differences on functioning scales between males and females within an age group are small but nonetheless favour males. The largest differences between sexes are seen in the emotional functioning scale, where females consistently have poorer functioning, ranging from a difference of 2.5 points for those aged 60–69 years to 8.1 for those aged 70 + years. Young males aged 18–39 years have worse physical functioning than young females (81.2 vs. 85.7); however, their emotional functioning (68.6 vs. 63.2) and global QoL is better (67.1 vs. 59.0). For symptoms, the differences between males and females within an age group are generally larger than for functioning scales. The level of symptomatology reported in males is lower than in females across age

Table 3
EORTC QLQ-C30 general population normative data for adults in the UK. Mean scores and standard deviations for functioning and symptom scales by sex, unweighted and weighted.

	Male			Female			
	Unweighted (N = 509) Mean (SD)	Weighted (N = 502) Mean (SD)	Difference (UW-W)	Unweighted (N = 517) Mean (SD)	Weighted (N = 524) Mean (SD)	Difference (UW-W)	Difference (M-F) (Weighted)
Functioning Scales							
Physical Functioning	81.0 (24.4)	80.6 (25.2)	0.4	81.4 (22.6)	83.0 (21.6)	-1.6	-2.4
Role Functioning	79.9 (29.1)	79.0 (29.8)	0.9	80.3 (29.8)	81.4 (28.4)	-1.1	-2.4
Emotional Functioning	75.7 (26.8)	73.4 (27.8)	2.3	70.2 (27.8)	68.6 (28.9)	1.6	4.8
Cognitive Functioning	82.0 (24.0)	80.5 (26.0)	1.5	81.4 (23.7)	80.5 (24.5)	0.9	0.0
Social Functioning	82.3 (27.9)	80.6 (28.8)	1.7	80.5 (29.5)	80.0 (29.9)	0.5	0.6
Global health status/QoL	63.0 (23.6)	63.9 (23.9)	-0.9	61.0 (24.0)	60.9 (23.5)	0.1	3.0
Symptom Scales							
Fatigue	29.6 (27.2)	30.7 (27.6)	-1.2	33.2 (28.0)	33.6 (27.7)	-0.4	-2.9
Nausea and vomiting	6.0 (17.0)	8.8 (20.8)	-2.8	6.7 (15.7)	7.3 (17.0)	-0.6	1.5
Pain	26.1 (31.0)	26.1 (31.0)	0.0	28.3 (31.7)	27.4 (31.3)	1.0	-1.3
Dyspnoea	19.8 (29.0)	20.9 (30.4)	-1.0	18.4 (25.8)	18.2 (25.2)	0.2	2.7
Insomnia	29.3 (32.5)	28.3 (32.4)	1.0	37.4 (32.9)	36.7 (32.8)	0.7	-8.4
Appetite loss	11.1 (23.0)	13.7 (25.3)	-2.6	13.4 (24.1)	14.6 (25.1)	-1.2	-0.8
Constipation	11.2 (23.7)	12.7 (25.6)	-1.5	15.5 (25.7)	16.6 (26.7)	-1.0	-3.9
Diarrhoea	9.7 (22.2)	12.3 (25.2)	-2.6	9.7 (20.0)	10.0 (20.6)	-0.4	2.3
Financial difficulties	12.3 (26.2)	15.0 (28.3)	-2.7	13.7 (28.6)	14.1 (29.1)	-0.3	0.9

SD = standard deviation; UW = unweighted; W = weighted; M = male; F = female; QoL = Quality of Life

Table 4
EORTC QLQ-C30 general population normative data for adults in the UK. Mean scores and standard deviations for functioning and symptom scales by age categories, weighted.

	18-39 (n = 400) Mean (SD)	40-49 (n = 170) Mean (SD)	50-59 (n = 164) Mean (SD)	60-69 (n = 137) Mean (SD)	70 + (n = 156) Mean (SD)	Range
Functioning Scales						
Physical Functioning	83.8 (23.2)	82.1 (26.6)	79.7 (24.2)	80.9 (22.1)	79.5 (20.7)	4.3
Role Functioning	80.4 (28.2)	78.8 (31.2)	75.5 (33.4)	81.4 (28.8)	85.0 (23.3)	9.5
Emotional Functioning	66.0 (30.1)	66.7 (30.3)	68.2 (30.1)	80.2 (21.6)	83.1 (18.8)	17.1
Cognitive Functioning	77.5 (28.3)	79.3 (26.7)	78.5 (26.5)	86.4 (18.4)	86.5 (15.6)	9.0
Social Functioning	77.5 (30.8)	78.1 (31.6)	78.0 (31.2)	84.7 (26.3)	88.3 (20.7)	10.8
Global health status/QoL	63.6 (22.9)	59.9 (25.9)	56.3 (26.0)	63.7 (22.3)	67.0 (20.3)	10.7
Symptom Scales						
Fatigue	34.5 (27.1)	31.9 (30.4)	35.7 (31.2)	28.5 (25.4)	26.3 (22.4)	8.2
Nausea and vomiting	12.9 (24.0)	8.1 (19.7)	5.2 (12.6)	3.6 (10.7)	2.5 (9.1)	10.4
Pain	25.4 (30.8)	26.1 (32.8)	31.6 (33.9)	27.2 (30.8)	25.2 (27.4)	6.4
Dyspnoea	20.7 (29.2)	17.3 (27.0)	20.9 (28.5)	17.1 (26.0)	19.4 (26.4)	3.8
Insomnia	30.5 (32.4)	33.3 (34.4)	40.0 (34.8)	32.9 (31.7)	29.3 (30.1)	10.7
Appetite loss	19.5 (28.4)	12.9 (24.3)	12.9 (24.7)	9.8 (20.9)	7.0 (17.8)	12.5
Constipation	18.2 (29.5)	14.4 (26.0)	13.1 (25.7)	9.5 (20.3)	12.0 (21.1)	8.7
Diarrhoea	15.1 (26.7)	11.2 (24.0)	11.4 (22.4)	5.0 (14.0)	6.2 (15.6)	10.1
Financial difficulties	19.1 (31.4)	18.1 (32.8)	15.7 (28.9)	8.8 (22.8)	2.6 (12.5)	16.5

SD = standard deviation; QoL = Quality of Life

groups, except for nausea/vomiting and diarrhoea in the youngest age group. Differences exceeding 10 points can be seen for insomnia in the two youngest age groups, and appetite loss and constipation in age group 40–49 years.

4. Discussion

Normative HRQoL data collected using the EORTC QLQ-C30 from the UK general population is presented. This panel research study identifies clinically meaningful differences between participant groups based on age, sex and age/sex subgroups, with largest differences seen between age bands regardless of sex. The tables can be used as look-up tables; providing a valuable resource for practitioners, researchers and clinical trialists in the UK to interpret self-reported HRQoL data collected from UK cancer patients via the EORTC QLQ-C30. An example is the NHS England Cancer QoL Survey [23].

The UK results are broadly consistent with the whole international sample [15]. Trends across age groups or between genders are similar to those reported in other European countries [20–22,24–26] in terms of direction, for example physical functioning decreases with increasing age, whilst emotional functioning increases and fatigue improves with age. However, the absolute values are consistently lower for functioning scales (poorer performance) and higher for symptoms (worse symptomatology). This might be explained by the large number of participants reporting at least one concurrent health condition. In our sample 62.8% report having an existing health condition. This can be compared with 63.4% for the whole international sample [15] and 47.9% in the Netherlands [22], 53.6% in Austria [20], 60.7% in Italy [25], 61.6% in

Table 5a
EORTC QLQ-C30 general population normative data for adult in the UK. Mean scores and standard deviations for functioning and symptom scales for males by age category, weighted.

	18-39 years		40-49 years		50-59 years		60-69 years		70 + years			ALL MALES	
	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Range	Mean	(SD)
<u>Functioning Scales</u>													
Physical Functioning	81.2	(26.3)	82.8	(26.4)	79.1	(23.6)	81.5	(23.6)	80.3	(21.8)	3.7	80.6	(25.3)
Role Functioning	79.5	(29.9)	79.4	(30.2)	74.9	(32.7)	81.2	(27.2)	84.8	(23.4)	9.9	79.0	(29.8)
Emotional Functioning	68.6	(29.5)	69.6	(31.5)	71.0	(29.6)	81.5	(18.9)	87.6	(15.1)	19.0	73.4	(27.8)
Cognitive Functioning	78.0	(29.6)	79.9	(27.4)	78.3	(26.2)	86.1	(18.0)	88.0	(12.9)	10.0	80.5	(26.0)
Social Functioning	78.0	(29.8)	78.9	(31.4)	80.3	(27.9)	84.2	(27.9)	90.1	(19.0)	12.1	80.6	(28.8)
Global health status/QoL	67.1	(23.2)	61.5	(24.9)	56.4	(25.7)	62.2	(21.9)	67.8	(20.1)	11.4	63.9	(23.9)
<u>Symptom Scales</u>													
Fatigue	32.4	(26.8)	27.9	(29.4)	33.9	(30.5)	28.1	(25.7)	25.3	(22.1)	8.6	30.7	(27.6)
Nausea and vomiting	15.4	(26.4)	6.6	(19.2)	4.3	(12.2)	2.0	(8.2)	1.7	(6.4)	13.7	8.8	(20.8)
Pain	25.4	(30.5)	24.7	(32.0)	31.6	(34.2)	28.3	(31.4)	20.3	(24.7)	11.3	26.1	(31.0)
Dyspnoea	21.4	(32.9)	17.4	(27.5)	21.6	(28.8)	16.7	(25.9)	22.1	(29.0)	5.4	20.9	(30.4)
Insomnia	25.9	(30.9)	28.2	(36.1)	37.5	(34.7)	29.7	(29.5)	25.1	(29.1)	12.4	28.3	(32.4)
Appetite loss	19.4	(28.1)	7.5	(18.2)	14.0	(26.4)	8.8	(19.2)	5.6	(17.6)	13.8	13.7	(25.3)
Constipation	15.5	(29.0)	8.8	(22.1)	10.2	(23.1)	8.2	(19.0)	13.2	(23.5)	7.3	12.7	(25.6)
Diarrhoea	17.8	(29.0)	10.9	(25.1)	11.1	(22.9)	5.2	(15.3)	3.3	(10.0)	14.5	12.3	(25.3)
Financial difficulties	21.0	(31.2)	15.7	(30.6)	11.4	(23.0)	10.5	(25.6)	3.0	(13.4)	18.0	15.0	(28.3)

SD = standard deviation; QoL = Quality of Life

Table 5b
EORTC QLQ-C30 general population normative data for adult in the UK. Mean scores and standard deviations for functioning and symptom scales for females by age category, weighted.

	18-39 years		40-49 years		50-59 years		60-69 years		70 + years		Range	ALL FEMALES	
	Mean	(SD)	Mean	(SD0	Mean	(SD)	Mean	(SD)	Mean	(SD)	Range	Mean	(SD)
<u>Functioning Scales</u>													
Physical Functioning	85.7	(19.9)	81.5	(26.7)	80.3	(24.8)	80.3	(20.5)	78.9	(19.7)	6.8	83.0	(21.6)
Role Functioning	80.5	(28.1)	78.2	(32.1)	76.0	(33.8)	81.6	(30.1)	85.1	(23.1)	9.1	81.4	(28.4)
Emotional Functioning	63.2	(29.8)	64.0	(28.7)	65.4	(30.3)	79.0	(23.6)	79.5	(20.5)	16.3	68.6	(28.9)
Cognitive Functioning	77.7	(26.7)	78.7	(26.0)	78.8	(26.7)	86.6	(18.7)	85.3	(17.2)	8.9	80.5	(24.5)
Social Functioning	77.2	(31.7)	77.4	(31.7)	75.9	(33.9)	85.2	(24.6)	86.9	(21.9)	11.0	80.0	(30.0)
Global health status/QoL	59.0	(22.3)	58.3	(26.6)	56.2	(26.1)	65.2	(22.5)	66.3	(20.4)	10.1	60.9	(23.5)
<u>Symptoms Scales</u>													
Fatigue	36.7	(27.8)	35.9	(30.7)	37.6	(31.7)	28.9	(25.0)	27.1	(22.5)	10.5	33.6	(27.7)
Nausea and vomiting	9.6	(19.3)	9.6	(20.0)	6.1	(13.0)	5.2	(12.4)	3.1	(10.6)	6.5	7.3	(17.0)
Pain	27.4	(32.7)	27.6	(33.4)	31.5	(33.5)	26.3	(30.1)	29.1	(28.6)	5.2	27.4	(31.3)
Dyspnoea	19.8	(24.6)	17.2	(26.4)	20.3	(28.1)	17.6	(26.0)	17.3	(23.7)	3.1	18.2	(25.2)
Insomnia	37.7	(33.8)	38.3	(31.7)	42.5	(34.7)	35.9	(33.3)	32.7	(30.3)	9.8	36.7	(32.8)
Appetite loss	18.2	(26.8)	18.2	(28.0)	11.8	(22.7)	10.7	(22.2)	8.2	(17.8)	10.1	14.6	(25.1)
Constipation	20.1	(29.3)	19.8	(28.3)	16.0	(27.5)	10.7	(21.3)	11.1	(18.9)	9.4	16.6	(26.7)
Diarrhoea	12.0	(22.1)	11.6	(22.8)	11.8	(21.7)	4.7	(12.5)	8.5	(18.5)	7.3	10.2	(20.6)
Financial difficulties	18.9	(31.8)	20.5	(34.5)	20.0	(33.1)	7.2	(19.5)	2.3	(11.7)	18.2	14.1	(29.1)

SD = standard deviation; QoL = Quality of Life

Spain [24] and 63.1% in Germany [21]. Knowledge of any other illnesses should be taken into consideration when using normative data as a comparator.

Age-group differences were observed for self-reported functioning, with the most striking clinically meaningful difference observed in emotional functioning. Regardless of sex, the youngest three age groups showed substantially worse scores compared with the two oldest age groups. Clinically meaningful differences were also observed in cognitive (males only) and social functioning (both sexes), with older participants reporting higher/better scores. This observation may be related to response shift effects [27], with older respondents adapting their expectations relative to their age, recalibrating the response scale of the EORTC QLQ-C30. Thus, older respondents may not truly be more capable than younger respondents in terms of cognitive functioning; their self-reported HRQoL is rather a reflection of their adapted expectations. However, for domains such as emotional or social functioning, differences may be real due to higher demands on younger persons in everyday life. The higher burden of financial difficulties in the younger age groups seems to support this. The four most prevalent symptoms are fatigue, pain, sleep and dyspnoea, and females experience higher symptom levels than males. For some symptoms, younger participants (especially age group 18–39 years) show more symptom burden than older participants. Observed subgroup differences provide insights into the HRQoL of the UK general population, highly relevant for interpreting UK cancer patients' self-reported HRQoL data.

Symptoms of diarrhoea, constipation, appetite loss and dyspnoea are not unique to cancer patients. They are experienced by many people on a regular basis as a consequence of some other condition or a side-effect of medication. And those without any other chronic health condition experience these symptoms periodically. The symptom scales DI, CO, AP, DY are all single items, with possible scores of 0, 33, 66 or 100. The median score for all 5 age categories is zero suggesting the data are skewed and there is floor effect. Whilst there is almost a three-fold difference for appetite between the youngest and oldest age groups (18.8 v 6.) and similar for Diarrhoea (14.8 v 5.9) the absolute values are small and the majority of participants scored 0 or 33.

The study has some limitations however, especially regarding the representativeness of the dataset. Data was collected via an online panel, registered with a market research company and required to have internet access. Every 10 years a census is conducted in the UK in

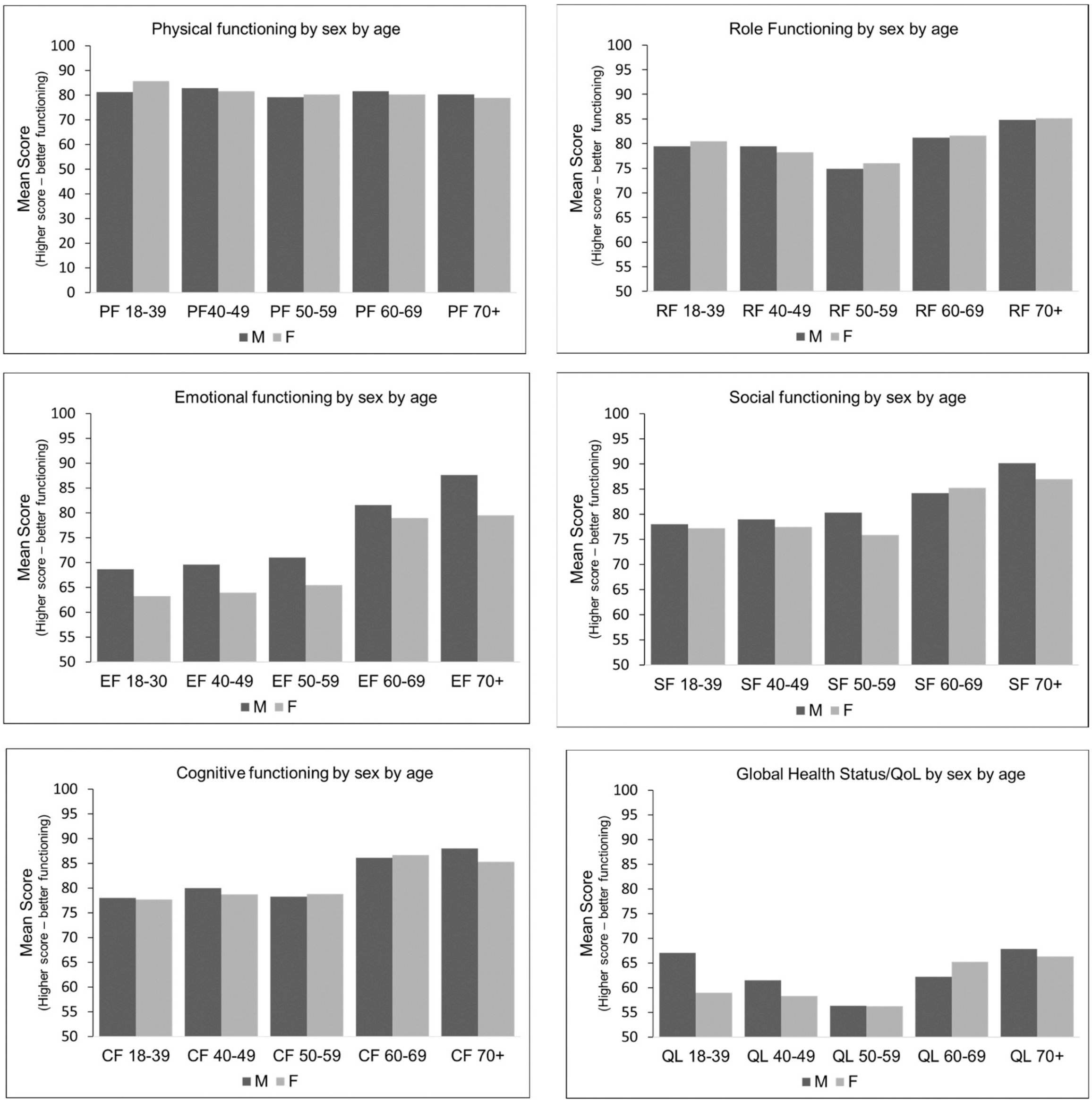

Fig. 1a. UK EORTC QLQ-C30 general population normative data for global health status/quality of life and functioning subscales for males and females by age category. (High scores denote good functioning).

England and Wales but not Scotland or Northern Ireland, most recently in 2021 [28]. Approximately 11% of the UK population live in Scotland or Northern Ireland but GfK did not provide details on areas sampled. From the census 99% of the population aged 16–44 years were recent internet users, falling to 47% for those > =75 years. So, the oldest group may be less representative of the UK general population due to differences in internet access. From the census 33.8% of those > =16 years reported their highest level of qualification as Level 4 (Higher National Certificate, Diploma, Degree or Postgraduate), in line with our sample (33.1%). However, the next most common census category was no qualification (18.2%), and only 1.5% of our sample had no qualifications. Those with a lack of educational qualifications and possibly poor literacy and lack of internet access are not represented in our sample. It is known that low educational attainment is linked to poor health [29] and such individuals are less likely to participate in surveys [30].

The 2021 census was conducted during the COVID pandemic, and our survey was conducted in 2017 so comparisons may not be reliable however, looking at weighted data in Table 2 the percentage of retirees is similar (23.6% v. 21.6%) whilst those "economically active" may be slightly under-represented (52.9% v. 60.6%). According to the census 19.3% of the population was not white-British whereas only 10.4% of our weighted sample identified as not white-British, so ethnic minority groups are under-represented. People from Asian ethnic groups made up the largest percentage (9.3%), followed by black (4.0%), mixed (2.9%) and other (2.1%). Geographical region and urban versus rural location also impact on the proportion of ethnic minorities. Only 36.8% of the population of London was white-British compared to 90.6% in Wales and North East England. Future studies collecting normative data should consider noting whether respondents live in an urban or rural area, and users of the data should consider the ethnic diversity of their local area.

5. Conclusion

To our knowledge, this is the first study providing EORTC QLQ-C30 general population normative data for the UK. The look-up tables are a highly relevant resource for the interpretation of HRQoL data as obtained from UK cancer patients. Observed subgroup differences, especially those between age bands that were larger than between males and females provide further important insights into the HRQoL of the UK general population that need to be taken into account when interpreting

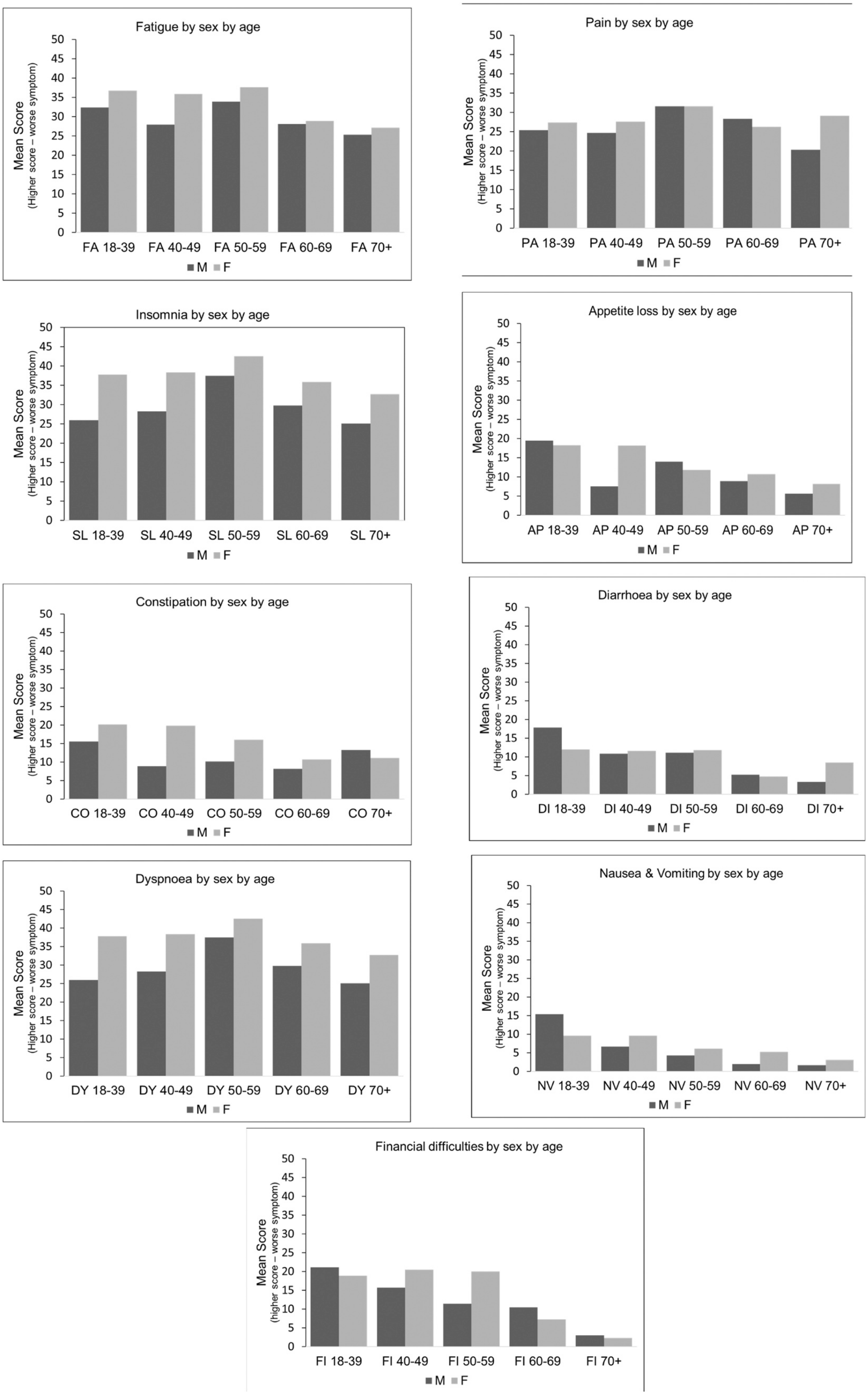

Fig. 1b. UK EORTC QLQ-C30 general population normative data for symptom subscales for males and females by age category. (High scores denote worse symptoms).

UK cancer patients' self-reported HRQoL.

Ethical statement

Ethical approval was not sought as the original European general population norm data study was solely based on panel research data. As opposed to medical research where medical professional codes of conduct apply, there is widespread agreement that health research involving volunteers from the general population is not subject to ethical approval. Both the European Pharmaceutical Market Research Association (EphMRA) and the NHS Health Research Authority specify that this type of research does not require ethical approval as long as the research conforms to ethical guidelines. Our online survey was carried out by the panel research company GfK SE which is member of EphMRA. The multinational survey conformed to the required ethical standards by obtaining informed consent from all participants and collecting data completely anonymously. Any identification of the respondents through the authors is impossible.

CRediT authorship contribution statement

Gregor Liegl: Writing – review & editing, Data curation. **Galina Velikova:** Writing – review & editing, Methodology. **Teresa Young:** Writing – original draft, Visualization, Methodology, Funding acquisition, Formal analysis. **Sandra Nolte:** Writing – original draft, Visualization, Supervision, Project administration, Methodology, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Matthias Rose:** Writing – review & editing, Funding acquisition.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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References

[1] Guyatt GH, Veldhuyzen Van Zanten SJ, Feeny DH, Patrick DL. Measuring quality of life in clinical trials: a taxonomy and review. Cmaj 1989;140:1441–8.
[2] Bottomley A, Flechtner H, Efficace F, Vanvoorden V, Coens C, Therasse P, et al. Health related quality of life outcomes in cancer clinical trials. Eur J Cancer 2005; 41:1697–709.
[3] Kluetz PG, Slagle A, Papadopoulos EJ, Johnson LL, Donoghue M, Kwitkowski VE, et al. Focusing on core patient-reported outcomes in cancer clinical trials: symptomatic adverse events, physical function, and disease-related symptoms. Clin Cancer Res 2016;22:1553–8.
[4] Kluetz PG, O'Connor DJ, Soltys K. Incorporating the patient experience into regulatory decision making in the USA, Europe, and Canada. Lancet Oncol 2018; 19:e267–74.
[5] Velikova G, Booth L, Smith AB, Brown PM, Lynch P, Brown JM, et al. Measuring quality of life in routine oncology practice improves communication and patient well-being: a randomized controlled trial. J Clin Oncol 2004;22:714–24.
[6] Absolom K, Warrington L, Hudson E, Hewison J, Morris C, Holch P, et al. Phase III randomized controlled trial of eRAPID: eHealth intervention during chemotherapy. J Clin Oncol 2021;39:734–47.
[7] Di Maio M, Basch E, Denis F, Fallowfield LJ, Ganz PA, Howell D, et al. The role of patient-reported outcome measures in the continuum of cancer clinical care: ESMO Clinical Practice Guideline. Ann Oncol 2022;33:878–92.
[8] King MT. A point of minimal important difference (MID): a critique of terminology and methods. Expert Rev Pharm Outcomes Res 2011;11:171–84.
[9] Guyatt GH, Osoba D, Wu AW, Wyrwich KW, Norman GR. Methods to explain the clinical significance of health status measures. Mayo Clin Proc 2002;77:371–83.
[10] Terwee CB, Peipert JD, Chapman R, Lai JS, Terluin B, Cella D, et al. Minimal important change (MIC): a conceptual clarification and systematic review of MIC estimates of PROMIS measures. Qual Life Res 2021;30:2729–54.
[11] Musoro JZ, Coens C, Sprangers MAG, Brandberg Y, Groenvold M, Flechtner H-H, et al. Minimally important differences for interpreting EORTC QLQ-C30 change scores over time: a synthesis across 21 clinical trials involving nine different cancer types. Eur J Cancer 2023;188:171–82.
[12] Giesinger JM, Loth FLC, Aaronson NK, Arraras JI, Caocci G, Efficace F, et al. Thresholds for clinical importance were established to improve interpretation of the EORTC QLQ-C30 in clinical practice and research. J Clin Epidemiol 2020;118: 1–8.
[13] Scott N.W., Fayers P., Aaronson N.K., Bottomley A., de Graeff A., Groenvold M., et al. EORTC QLQ-C30 Reference Values Manual (2nd ed,). 2008.
[14] Hinz A, Singer S, Brähler E. European reference values for the quality of life questionnaire EORTC QLQ-C30: Results of a German investigation and a summarizing analysis of six European general population normative studies. Acta Oncol 2014;53:958–65.
[15] Nolte S, Liegl G, Petersen MA, Aaronson NK, Costantini A, Fayers PM, et al. General population normative data for the EORTC QLQ-C30 health-related quality of life questionnaire based on 15,386 persons across 13 European countries, Canada and the Unites States. Eur J Cancer 2019;107:153–63.
[16] Aaronson NK, Ahmedzai S, Bergman B, Bullinger M, Cull A, Duez NJ, et al. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. J Natl Cancer Inst 1993;85:365–76.
[17] Fayers P., Aaronson N.K., Bjordal K., Groenvold M., Curran D., Bottomley A., et al. EORTC QLQ-C30 Scoring Manual (3rd edition). 2001.
[18] United Nations Department of Economic and Social Affairs Population Division. World Population Prospects: the 2017 revision. DVD Edition. 2017.
[19] Osoba D, Rodrigues G, Myles J, Zee B, Pater J. Interpreting the significance of changes in health-related quality-of-life scores. J Clin Oncol 1998;16:139–44.
[20] Lehmann J, Giesinger JM, Nolte S, Sztankay M, Wintner LM, Liegl G, et al. Normative data for the EORTC QLQ-C30 from the Austrian general population. Health Qual Life Outcomes 2020;18:275.
[21] Nolte S, Waldmann A, Liegl G, Petersen MA, Groenvold M, Rose M, et al. Updated EORTC QLQ-C30 general population norm data for Germany. Eur J Cancer 2020; 137:161–70.
[22] de Ligt KM, Aaronson NK, Liegl G, Nolte S, Group EQoL. Updated normative data for the EORTC QLQ-C30 in the general Dutch population by age and sex: a cross-sectional panel research study. Qual Life Res 2023;32:2477–87.
[23] NHS England. Cancer Quality of Life Survey. 〈https://www.cancerdata.nhs.uk/cancerqol〉; 2023.
[24] Arraras JI, Nolte S, Liegl G, Rose M, Manterola A, Illarramendi JJ, et al. General Spanish population normative data analysis for the EORTC QLQ-C30 by sex, age, and health condition. Health Qual Life Outcomes 2021;19:208.
[25] Pilz MJ, Gamper EM, Efficace F, Arraras JI, Nolte S, Liegl G, et al. EORTC QLQ-C30 general population normative data for Italy by sex, age and health condition: an analysis of 1,036 individuals. BMC Public Health 2022;22:1040.
[26] Johansson H, Lagergren P, Nolte S, Brandberg Y. Comparison between Swedish EORTC QLQ-C30 general population norm data published in 2000 and 2019. Acta Oncol 2023;62:1592–8.
[27] Sprangers MA, Schwartz CE. Integrating response shift into health-related quality of life research: a theoretical model. Soc Sci Med 1999;48:1507–15.
[28] Office for national Statistics. UK Census. 〈https://www.ons.gov.uk/census〉; 2021.
[29] Eide ER, Showalter MH. Estimating the relation between health and education: what do we know and what do we need to know? Econ Educ Rev 2011;30:778–91.
[30] Spitzer S. Biases in health expectancies due to educational differences in survey participation of older Europeans: It's worth weighting for. Eur J Health Econ 2020; 21:573–605.