

# BMJ Open Exploration of whether socioeconomic factors affect the results of priority setting partnerships: updating the top 10 research priorities for the management of Parkinson's in an international setting

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## ABSTRACT

**Objectives** Explore whether socioeconomic differences of patients affect the prioritisation of pre-existing research questions and explore the agreement between healthcare professionals (HCP) and patients in priority setting partnerships (PSPs).

**Design and setting** Prospective, three centre survey across UK (400 participants), Tuebingen (176 participants) and Luxembourg (303 participants). People with Parkinson's (PwP), research participants, relatives and HCP associated with three Parkinson's cohort studies were invited to participate, along with linked centres (clinical care settings, research groups, charities). Responders were encouraged to pass on the survey to friends/families/carers.

**Methods** The survey involved rating the importance of research questions on a Likert scale, allowing for the generation of one new question participants felt was particularly important. Collection of demographic information allowed for comparisons of priorities across a range of socioeconomic variables; the top 10 research priorities for each group were then compared. Questions added by participants were subject to a thematic analysis.

**Results** 879 participants completed the survey (58% PwP, 22% family/friends, 13% HCP, 4% carers). Finding the best form of physiotherapy for PwP was the number one priority across the majority of analyses. HCP were the only subgroup not to place physiotherapy in the top 10. Factors most likely to affect prioritisation in PwP included educational level, presence of carer support and disease duration. There was little difference between other socioeconomic categories.

**Conclusions** Socioeconomic factors modestly influenced some research priority ratings but did not significantly affect the top priority in most comparisons. Future studies must ensure patients from a range of socioeconomic backgrounds are recruited, ensuring results generalisable to the public while also identifying any key disparities in prioritisation. PSP should also take care that HCP do not skew results during prioritisation of questions, as in this study the most important priority to patients was not identified by professionals.

## Strengths and limitations of this study

- ⇒ This is the first priority setting partnership (PSP) to explore the influence of socioeconomic factors on the prioritisation of research questions, exploring their role across several European Parkinson's centres.
- ⇒ A large sample of 879 participants completed the survey to rate the priority questions.
- ⇒ Despite best efforts, there were limited responses from ethnic minorities and from people supported by carers or in care/nursing homes.
- ⇒ Conducted only in Western Europe, therefore, may not be generalisable to an international audience.

## INTRODUCTION

Priority setting partnerships (PSPs) (online supplemental material table S1) aim to make research more meaningful to patients by ascertaining the questions about medical conditions that are of the greatest importance to patients, their friends/family members and associated healthcare professionals (HCP).<sup>1,2</sup> Developing questions with a focus on the effectiveness of treatment options and care provision important to patients could improve participation in clinical trials, better inform research funding strategies and improve healthcare policies for patients; instead of the influence from 'big pharma'.<sup>3-5</sup> It has not previously been explored how socioeconomic factors affect the prioritisation of these questions. PSP groups vary in methodology but normally follow a format whereby:<sup>6,7</sup>

1. 'Research uncertainties' (subjects not yet answered) are generated by stakeholders through survey.

2. Uncertainties are turned into questions following systematic search of research databases.
3. The identified questions are ranked in order during an interim survey to form a smaller list of questions.
4. The reduced list is then ranked by a steering group to produce the final top 10 priorities.

Parkinson's is a neurodegenerative disorder (symptoms include rigidity and tremor), with depression, dementia and mild cognitive impairment being more prevalent in people with Parkinson's (PwP).<sup>8–14</sup> It has been hypothesised there are different subtypes of Parkinson's, contributing to the heterogeneity of symptoms observed in the clinical setting.<sup>12 15–18</sup> This could be problematic when trying to achieve consensus in research priorities, as Parkinson's experience can differ substantially. Furthermore, Parkinson's priorities for research topics may change depending on confounders (eg, disease duration and socioeconomic factors).

In 2014, research priorities for the management of Parkinson's were identified (online supplemental material figure S1) by a focus group led by Parkinson's UK, comprising 27 participants after an interim ranking round with 475 participants.<sup>19</sup> Results were subsequently presented at the 2016 Oxford Parkinson's Disease Centre (OPDC) cohort participant open day where attendees were asked to rate the list; results differed significantly. We therefore decided to formally explore whether socioeconomic differences influenced research priorities within CENTRE-PD, a Horizon2020 project allowing University of Luxembourg (UL), University of Tübingen (EKUT) and University of Oxford (UOXF) to share expertise, synchronise research cohort protocols giving greater statistical strength to analyses and enable ease of replication of studies and processes.<sup>20</sup> This study also aims to include more HCP; a limitation in the 2014 study.<sup>19</sup> Fundamentally, the three centre cohort studies are longitudinal, observational studies following PwP, at-risk people and age-matched controls to better understand the pathological pathways of Parkinson's.<sup>21–25</sup> As the cohorts are based in different countries, geographical comparisons can be made to see if there are any cross-cultural differences, something previously not done.<sup>19</sup>

## OBJECTIVES

The primary aims of this study were to explore:

- ▶ Whether research priorities for the management of Parkinson's change based on geographical location or other socioeconomic factors.
- ▶ Whether priorities of researchers/HCP align with that of PwP.

The secondary outcome from this was an updated research priorities list into Parkinson's management, and provide guidance on future systematic review questions that are important to PwP.

## METHODS

### Generation of questions

In the 2014 study,<sup>19</sup> 94 questions were created for ranking using a typical PSP method. There was concern too

many questions would make attention retention difficult for respondents, be too time consuming and reduce responses from our cohort participants. Therefore, the top 26 priorities (online supplemental material figure S2) from the interim ranking round were deemed sufficient. During the informal survey at the OPDC cohort open day, of the 147 responses, nine statements were included pertaining to speech difficulties. As this was of particular interest to our participants, we included this as a question in our survey. We also gave a free-text element option, allowing participants to write down a question they felt had been missed. Thus, the survey had 27 questions to rate, with an additional free-text question.

### Participant recruitment

Based on the median number of participants (n=386) (online supplemental material table S2) in JLA interim surveys, we aimed to recruit >400 people. There were no specific eligibility criteria as this was a feedback survey. All participants of the research cohorts associated with CENTRE-PD were invited to complete the survey once by post and/or email between July 2018 and January 2019. Cohort participants were invited to share the survey with friends/family as we were interested in the views of all people affected by Parkinson's. Members of email lists associated with the cohorts, study centres or CENTRE-PD were invited, Parkinson's UK also distributed the survey to interested persons. The rating pack and link for voluntary completion were sent by email to HCPs. Oxfordshire care homes were contacted twice to encourage responses from carers, nurses and PwP living there, (these people were identified as least likely to respond and likely to have lived with Parkinson's for longer). The survey was published by local research outreach teams, the hospital trust website, in hospital staff bulletins, university department bulletins, on the OPDC website, the OPDC and trust social media accounts, and in the local National Institute for Health Research (NIHR) newsletter. In Luxembourg the German and French paper version of the rating pack was sent with the newsletter to 646 patients and 996 controls of the Luxembourg Parkinson's study. PwP were invited to share the survey with friends/family. Additionally, about 700 HCPs receiving the newsletter were invited to complete the online version. Tuebingen contacted 243 people via email, as well as recruited participants at a patients' day.

### Patient and public involvement

Patients, their partners, family and related HCP from three cohort studies across Europe were invited to complete a survey asking about their sociodemographic variables (online supplemental material tables S3–S5 and figures S3–S5) and to rank their priorities for research into Parkinson's disease. Results of the study were disseminated via patient newsletter.

### Completing the survey

Parkinson's UK were contacted for permission to adapt literature created during their PSP group and a rating

pack was created. The survey and rating pack were translated at each site using the WHO process of translation and adaptation of instruments.<sup>26</sup> At the UOXF, the online version priority questions were presented in a random order (by the software) to reduce the risk of the same question(s) repeatedly being missed. The average, online survey completion time was 11 min (data from UOXF).

Surveys partially completed were assessed for inclusion or had the following imputations:

- ▶ If responder type was missing the survey was excluded.
- ▶ If demographic information was missing, 'prefer not to say' was selected.
- ▶ If 30% or more of the questions for rating were missed, the response was excluded.
- ▶ If fewer than 30% of the ratings were missed, the median score was imputed. There was a total of 118 imputed data points across all priority questions (0.5% of total ratings), with Q5, Would the monitoring of dopamine levels in the body (eg, with blood tests) be helpful in determining medication timing and amount (dose)? missed the most (n=10 missing data points).

### Analysis

To compare priorities between socioeconomic groups of PwP, we collected the following information:

- ▶ Participant type.
- ▶ Geographical location.
- ▶ Disease duration\*.
- ▶ Gender\*.
- ▶ Ethnicity (UOXF only)\*.
- ▶ Education level\*.
- ▶ Economic status\*.
- ▶ Living arrangements\*.

(online supplemental material figures S6–S14).

\*For PwP analysis

To calculate the top 10 for each subgroup, questions were ordered by the percentage agreeing that it was a high priority (score 7–9) (online supplemental material tables S6–S13). Where this was not sufficient to produce the top 10, median, IQR and range of scores were included. In one analysis this was still insufficient and the number of participants who voted the priority as nine had to be used.

To compare agreement between subgroups of whether each of the 27 primary questions were in the top 10 or not for that subgroup, Cohen's kappa (K) tests were run (online supplemental material tables S14–S22). Interpretation recommendations were used where: 0.41–0.60 was moderate agreement, 0.61–0.80 substantial, and 0.81–1.00 near perfect agreement.<sup>27 28</sup> For comparison of the score distributions of each priority question, Mann-Whitney-Wilcoxon (MWW) or Kruskal-Wallis (KW) test was used, as required by the number of subgroups analysed.

For the thematic analysis of added questions, each question was associated with up to four themes (eg, 'gut microbiota') by two raters autonomously, before convening to establish agreement. Where necessary, a third team member gave input. Themes were then grouped and

counted, and the ten most recurring themes were made into research questions.<sup>29</sup>

### RESULTS

In total, 1196 people responded to the survey, of which 879 were included for analysis (figure 1 and table 1). In the pooled analysis to establish the top 10 research priorities for Parkinson's, the joint first questions (79.1% agreement) were:

- ▶ Q19 'What is the best type and dose of exercise (physiotherapy) for improving muscle strength, flexibility, fitness, balance and function in people with Parkinson's?'
- ▶ Q9 'What drug treatments are best for the different stages of Parkinson's?'

The CENTRE-PD top 10 is displayed in table 2; the descriptive statistics for all questions are presented in table 3 with added questions presented in table 4. Table 5 highlights the top 10 research priorities and the ranking, as rated by each subgroup for visual comparison.

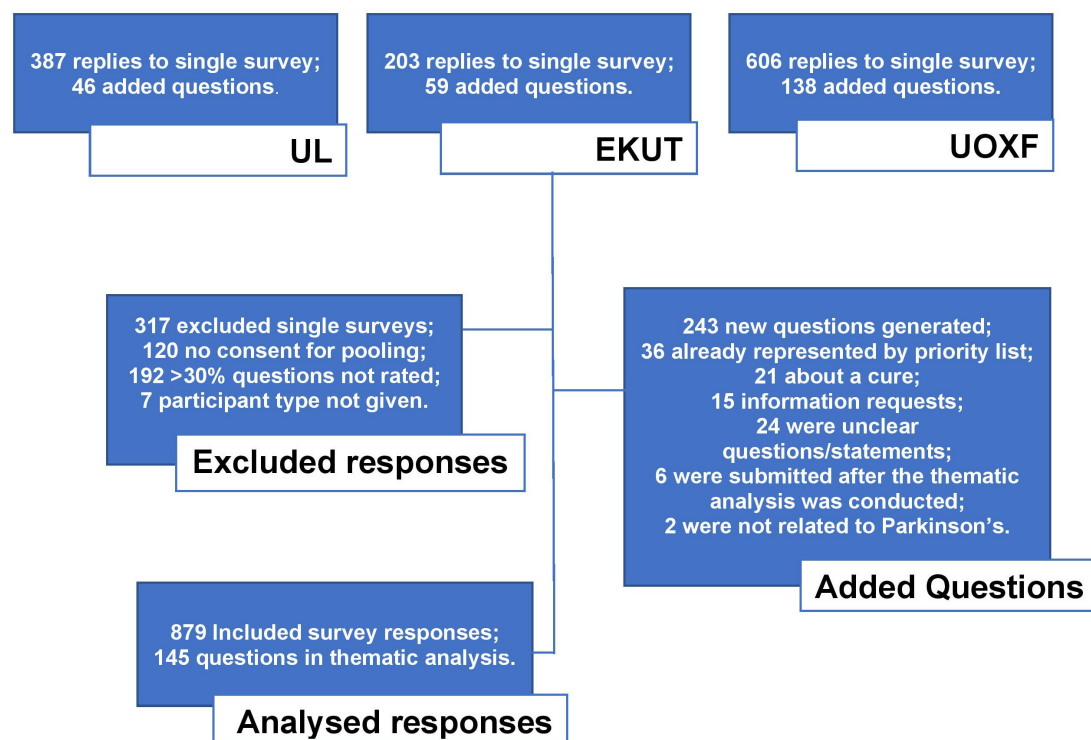
### Alignment of PwP and HCP priorities

Of the included participants, there were 511 PwP and 112 HCPs; they shared eight top 10 research priorities (online supplemental material table 23). The number one priority for HCP was Q2 ('hat treatments are helpful for reducing balance problems and falls in people with Parkinson's?') (88% agreement), which was ranked third by PwP. For PwP, the number one priority was Q19 (79% agreement). Q6 ('What is helpful for improving the quality of sleep in people with Parkinson's?'; 68% agreement) ranked 10th; neither made the HCP top 10 (joint 13th). Priorities ranked in the top 10 by HCP but not by PwP were Q14 ('What best helps prevent or reduce freezing (of gait and in general) in people with Parkinson's?') (18th in PwP) and Q15 ('What treatments are helpful for swallowing problems (dysphagia) in people with Parkinson's?') (23rd in PwP). The K score between HCP and PwP on the final top 10 was 0.682, or 68.2%, representing a substantial strength of agreement ( $p < 0.001$ ). In MWW tests to compare distributions of priority questions, PwP had a statistically significant lower mean rank, or lower distribution, in several questions compared with HCP ( $p = 0.00–0.041$ ).

### Disease duration

In the 490 responses from PwP, median disease duration was 5 years (IQR 3–9) which was similar across sites (medians: UL 5, EKUT, 6, UOXF 5), with a range of 0–41 years. To compare the effect disease duration had on the scoring of priority questions, disease duration was divided into quartiles: 0–3 years (n=146), 3–5 years (n=115), 5–9 years (n=126) and 9+ years (n=103). All quartile groups shared seven of the top 10 questions.

Between 0–3 years and 5–9 years, there was moderate agreement ( $k = 52.4%$ ,  $p = 0.007$ ), both of which had



**Figure 1** Study flow chart of responses (response summary, exclusions, added questions and final data for analysis). EKUT, University of Tübingen; UL, University of Luxembourg; UOXF, University of Oxford.

unique selections: 0–3 years was the only group to select Q1 (‘What treatments are helpful in reducing tremor in people with Parkinson’s?’) and omit Q6; 5–9 years were the only to select Q16 (‘What is the best method of monitoring a person with Parkinson’s response to treatments?’) and not include Q20 (‘Can medications be developed to allow fewer doses per day for people with Parkinson’s?’). There was good interrater reliability in other group analyses ( $K=68.2\%–84.1\%$   $p<0.001$ ). KW testing did not find any statistically significant differences in distribution of scores between these quartile groups (online supplemental material table S24).

### Education level

European guidance on Education Levels was used<sup>30</sup> and 482 PwP gave education information: group 1 (level 1–2,  $n=64$ ); group 2 (level 3–4,  $n=135$ ); group 3 (level 5–6,  $n=128$ ); group 4 (level 7–8,  $n=155$ ). Only five questions were consistently in the top 10 for all groups. Q19 was

top priority for groups 1–3, but was second for group 4, after Q9. Rater reliability between the two highest education groups was excellent ( $K=84.1\%$ ,  $p=0.00$ ) although order and distribution differed. The reliability between group 1 and other groups was less certain (20.6%–52.4%,  $p=0.007–0.285$ ). In KW testing, group 1 had a significant higher distribution for three questions compared with other groups and group 4 had a statistically significant lower distribution than other groups for multiple questions (online supplemental material tables S25–S43).

### Living arrangements

The majority of PwP were still living independently at home ( $n=331$ ), followed by living at home supported by family members ( $n=123$ ). Despite best efforts to increase responses from residential and nursing homes, response levels remained very low ( $n=6$ ). They were grouped with participants living at home supported by carers ( $n=19$ ) and analysed as supported by carer ( $n=25$ ).

Q19 was top priority for all groups and between the subgroups, seven of the priorities were the same. There was substantial agreement ( $K=68.2\%$ ), between ‘Independent’ and ‘Supported by Family’ participants ( $p<0.001$ ), and ‘Supported by Family’ and ‘Supported by Carer’ ( $p=0.007$ ). Agreement between ‘Independent’ and ‘Supported by Carer’ was moderate, (52.4%,  $p<0.001$ ). KW testing found significantly different distributions between ‘Supported by Carer’ and other groups for Q5, ‘Would the monitoring of dopamine levels in the body (eg, with blood tests) be helpful in determining medication timing and amount (dose)?’, (vs independent,

**Table 1** Percentage of responses by stakeholder group at each site

Cohort site	Stakeholder group		
	PwP (%)	HCP (%)	Other (%)
Luxembourg	38	24	38
Tubingen	90	4	6
UK	59	8	33

HCP, healthcare professional; PwP, people with Parkinson’s.

**Table 2** The final top 10 research priorities from pooled analysis of all sites and participants

CENTRE-PD top 10 research priorities for Parkinson's				
(n=879)				
Rank	Question no	Question	N who ranked ≥7	% Agreement
1*	19	What is the best type and dose of exercise (physiotherapy) for improving muscle strength, flexibility, fitness, balance and function in people with Parkinson's?	695	79.1
1	9	What drug treatments are best for the different stages of Parkinson's?	695	79.1
3	2	What treatments are helpful for reducing balance problems and falls in people with Parkinson's?	690	78.5
4	21	What helps improve the dexterity (fine motor skills or coordination of small muscle movements) of people with Parkinson's so they can do up buttons, use computers, phones, remote controls etc?	673	76.6
5	4	What treatments would ensure the medications were equally effective each day (prevented/managed wearing off, variability, on/off states) in people with Parkinson's?	667	75.9
6	7	What best treats mild cognitive problems such as memory loss, lack of concentration, indecision and slowed thinking in people with Parkinson's?	662	75.3
7	1	What treatments are helpful in reducing tremor in people with Parkinson's?	645	73.4
8	23	What is the best treatment for stiffness (rigidity) in people with Parkinson's?	626	71.2
9	3	Is it possible to identify different types of Parkinson's, for example, tremor dominant? And can we tailor treatments best according to these different types?	624	71.0
10	6	What is helpful for improving the quality of sleep in people with Parkinson's?	615	70.0

\*Number 1 in the majority of subanalyses therefore, listed above Q9.

p=0.002; vs supported by family, p=0.005) and Q17, 'What training, techniques or aids are needed for hospital staff, to make sure patients with Parkinson's get their medications correctly and on time?' (vs independent, p=0.41). In both, there was a higher median, IQR and distribution of scoring from the carer group (online supplemental material tables S44–S47).

### Local institute/geographical location

The response by institute was; UL, n=303; EKUT, n=176 and UOXF, n=400. The number one priority for EKUT was Q19. UOXF had Q19 and Q9 as joint first. The number one priority at UL was Q2; Q19 was ranked sixth by UL. There was substantial agreement between UL and EKUT, sharing 8 of 10 priorities (K=68.2%, p<0.01). Between UOXF and UL, and UOXF and EKUT, agreement was moderate (K=52.4%, p=0.007 for both comparisons), sharing 7 out of 10 priorities as the only institute to include Q6 and omit Q23 'What is the best treatment for stiffness...?'. There were significant differences in the distribution of scores between the centres in KW testing. UL was significantly different in 10 questions, tending to have a higher scoring distribution (p=0–0.035). UOXF were significantly different in 10 questions, usually with a lower scoring distribution (p=0–0.048) (online supplemental material tables S48–S73).

### Gender

The PwP group was predominantly male (n=312) (female, n=192; Prefer not to say, n=7). Women and men with

Parkinson's shared 9 of the top 10 priorities: both rated Q19 as the number one priority. Men rated Q1 as fourth, but this did not feature in the women's top 10 (14th). Women had Q6 at seventh however, this did not feature in the men's top 10 (11th). There was excellent agreement in the final top 10 priorities between women and men with Parkinson's (K=84.1% p<0.001). In MWW testing, comparing men to women, women had a higher mean rank in 12 of the priority questions (p=0.001–0.049).

### Economic status

The majority of PwP were living above the poverty line (n=372). People above and below poverty shared 8 of the top 10 priorities and Q19 was number one priority for both groups. There was significant reliability between groups (K=68.2% p<0.001). Above poverty line ranked Q6 and Q3 ('Is it possible to identify different types of Parkinson's, for example, tremor dominant? And can we tailor treatments best according to these different types?') in the top 10; below poverty line ranked Q16 and Q20 instead. MWW found significant differences in the distribution of two questions, Q5 (p=0.04) and Q16 (p=0.03).

### Ethnicity

91.6% (n=217) of UOXF PwP responders were white ethnicity. Due to limited responses from Black, Asian and minority ethnic groups (BAME), responses were grouped together but only 11 participants made up the BAME group (excluding non-identifiable text responses from

**Table 3** The summary statistics of all priority questions from pooled analysis of all sites and participants

Descriptive statistics for all questions							
(n=879)							
Rank	Question no	Question	Median	IQR1	IQR2	N who ranked ≥7	% Agreement
7	1	What treatments are helpful in reducing tremor in people with Parkinson's?	8	6	9	645	73.4
3	2	What treatments are helpful for reducing balance problems and falls in people with Parkinson's?	8	7	9	690	78.5
9	3	Is it possible to identify different types of Parkinson's, for example, tremor dominant? And can we tailor treatments best according to these different types?	8	6	9	624	71.0
5	4	What treatments would ensure the medications were equally effective each day (prevented/managed wearing off, variability, on/off states) in people with Parkinson's?	8	7	9	667	75.9
24	5	Would the monitoring of dopamine levels in the body (eg, with blood tests) be helpful in determining medication timing and amount (dose)?	7	6	8	532	60.5
10	6	What is helpful for improving the quality of sleep in people with Parkinson's?	7	6	9	615	70.0
6	7	What best treats mild cognitive problems such as memory loss, lack of concentration, indecision and slowed thinking in people with Parkinson's?	8	7	9	662	75.3
13	8	What treatments are helpful in reducing urinary problems (urgency, irritable bladder, incontinence) in people with Parkinson's?	7	6	9	580	66.0
1	9	What drug treatments are best for the different stages of Parkinson's?	8	7	9	695	79.1
19	10	What approaches are helpful for reducing stress and anxiety in people with Parkinson's?	7	6	8	557	63.4
12	11	What treatments are helpful for reducing dyskinesias (involuntary movements, which are a side effect of some medications) in people with Parkinson's?	7	6	8	589	67.0
11	12	What best treats dementia in people with Parkinson's?	8	6	9	607	69.1
23	13	What interventions are effective for reducing or managing unexplained fatigue in people with Parkinson's?	7	6	8	539	61.3
13	14	What best helps prevent or reduce freezing (of gait and in general) in people with Parkinson's?	7	6	9	580	66.0
16	15	What treatments are helpful for swallowing problems (dysphagia) in people with Parkinson's?	7	6	9	566	64.4
19	16	What is the best method of monitoring a person with Parkinson's response to treatments?	7	6	8	557	63.4
26	17	What training, techniques or aids are needed for hospital staff, to make sure patients with Parkinson's get their medications correctly and on time?	7	5	8	525	59.7
18	18	What treatments are helpful in reducing bowel problems (constipation, incontinence) in people with Parkinson's?	7	6	8	562	63.9
1	19	What is the best type and dose of exercise (physiotherapy) for improving muscle strength, flexibility, fitness, balance and function in people with Parkinson's?	8	7	9	695	79.1
15	20	Can medications be developed to allow fewer doses per day for people with Parkinson's? (For example combinations of medications in one pill, slow release pills)	7	6	9	577	65.6
4	21	What helps improve the dexterity (fine motor skills or coordination of small muscle movements) of people with Parkinson's so they can do up buttons, use computers, phones, remote controls etc?	8	7	9	673	76.6

Continued

**Table 3** Continued

Descriptive statistics for all questions							
(n=879)							
Rank	Question no	Question	Median	IQR1	IQR2	N who ranked ≥7	% Agreement
27	22	What treatments are effective in reducing hallucinations (including vivid dreams) in people with Parkinson's?	7	5	8	468	53.2
8	23	What is the best treatment for stiffness (rigidity) in people with Parkinson's?	8	6	9	626	71.2
21	24	At which stage of Parkinson's is deep brain stimulation (a surgical treatment that involves implanting a 'brain pacemaker' that sends signals to specific parts of the brain) most helpful?	7	6	8	553	62.9
25	25	What training to improve knowledge and skills do informal carers (family and friends) need in order to best care for people with Parkinson's?	7	6	8	528	60.1
16	26	What is the best treatment for pain in people with Parkinson's?	7	6	8	566	64.4
22	27	What speech therapy techniques are helpful for communication problems in people with Parkinson's?	7	5	8	542	61.7

'Other' group such as 'Welsh'). It was not possible to be certain of the top 10 priorities for BAME group or individual ethnicity groups as the numbers were too small to compare nor draw any conclusions from.<sup>31</sup>

#### Comparison with the 2014 Parkinson's PSP

Comparing the CENTRE-PD top 10 to the final top 10 published by Deane *et al*<sup>19</sup> showed poor agreement, with only 5 of the top 10 questions shared across both studies (K=20.6%, p=0.285). There was better agreement between the interim ranking round of the 2014 study and the CENTRE-PD top 10, sharing seven of the top 10 (K=52.4%, p=0.007).<sup>19</sup>

#### Added questions

A total of 243 participants added a statement/question during the survey for thematic analysis. Like the 2014 group, questions pertaining to a cure were removed as this is the overarching theme of Parkinson's research and would potentially take merit from other important questions. Other exclusion reasons included: the statement was an unclear question (eg, 'hair loss') or it was an information request (eg, 'is deep brain stimulation available on the National Health Service?') (figure 1). A total of 145 entries remained. The most common recurring

**Table 4** Top 10 added questions from thematic analysis

Question no	Added question	Count (%)
28	What is the best treatment for low-mood/depression in PwP?	21 (14.5)
29	Which non-medication alternative therapies (eg, hypnosis, acupuncture etc) help to treat or manage Parkinson's?	13 (9)
30	How can Parkinson's be identified earlier?	12 (8.3)
31	Which genes predict Parkinson's, the severity of progression, and the likelihood of developing non-motor complications?	9 (6.2)
32	What is the best way to educate PwP on living with Parkinson's, managing symptoms, and accessing high quality information/support?	8 (5.5)
33	How can healthcare professionals be better educated in caring for, treating and monitoring PwP to ensure high quality care is always given (in both primary and secondary settings)?	8 (5.5)
34	Which dietary supplements in particular cannabis, help manage Parkinson's?	7 (4.8)
35	What effect do medications for other conditions (eg, beta-blockers, chemotherapy), have on Parkinson's symptoms and how can this be monitored more effectively?	6 (4.1)
36	What role does gut health (including use of probiotics) have in Parkinson's?	6 (4.1)
37	How can apathy be more easily identified and managed in Parkinson's?	6 (4.1)

PwP, people with Parkinson's.



**Table 5** Ranking results of priority questions from all subgroup analyses

Question no	Participant type		Disease duration					Education level					Living arrangements					Geographical location					Gender		Economic status	
	Final top 10s		0-3 years (n=146)	3-5 years (n=115)	5-6 years (n=126)	9+ years (n=103)	Level 1-2 (n=64)	Level 3-4 (n=135)	Level 5-6 (n=128)	Level 7-8 (n=155)	Living Independently (n=331)	Supported by Family (n=123)	Supported by Carers (n=25)	UL (n=303)	EKUT (n=176)	UOXF (n=400)	Male (n=312)	Female (n=192)	Above Poverty Line (n=372)	Below Poverty Line (n=73)						
1	seventh	second	third	fourth	first	second	tenth	fifth	seventh	sixth	seventh	second	third	tenth	tenth	fourth	third	tenth	fourth							
2	third	first	seventh	fourth	first	fourth	sixth	fifth	fifth	sixth	third	second	first	eighth	fourth	third	sixth	fifth	second							
3	ninth	fourth	ninth	seventh	fourth	fourth	third	ninth	fourth	fourth					fifth	eighth	ninth	sixth								
4	fifth	fifth	sixth	sixth	sixth	second	tenth	fourth	third	fifth	fourth	eighth	fourth	second	eighth	fifth	fifth	third	tenth							
5										fourth																
6	tenth	eighth	tenth	eighth	ninth	eighth	tenth	eighth	tenth	second	second				sixth	seventh	seventh	eighth								
7	sixth	sixth	fourth	tenth	eighth	tenth	eighth	sixth	eighth	eighth	third	third	fifth	third	seventh	sixth	eighth	sixth								
8	tenth	tenth					ninth																			
9	first	ninth	second	second	third	third	second	second	first	second	fifth	fifth	second	fourth	first	second	second	second	third							
10	second	second				eighth																				
11	third	third	tenth	seventh	seventh	fifth																				
12	fifth	fifth																								
13							tenth							ninth												
14		sixth								tenth																
15		seventh					seventh			ninth	ninth	ninth	ninth	ninth	ninth	ninth	ninth	ninth	ninth							
16		seventh			tenth		seventh			sixth	seventh	seventh	seventh	ninth	ninth	ninth	ninth	ninth	ninth							
17																										
18																										
19	first	first	second	first	first	first	first	first	second	first	first	first	sixth	first	first	first	first	first	first							
20			eighth	fifth	fifth	ninth	fifth	tenth	tenth	tenth	tenth	tenth	seventh	seventh	tenth	tenth	tenth	tenth	eighth							
21	fourth	ninth	fifth	third	fifth	ninth	second	fourth	third	third	tenth	tenth	seventh	fifth	third	seventh	third	fourth	sixth							
22																										
23	eighth	ninth	seventh	ninth	seventh	sixth	fourth	seventh	sixth	ninth	eighth	sixth	seventh	fifth	ninth	fourth	ninth	ninth	fifth							
24																										
25																										
26																										
27																										

Colour Key: Dark Blue - ranked first; Blue - ranked second; Light Blue - ranked third. EKUT, University of Tübingen; HCP, healthcare professional; PWP, people with Parkinson's; UL, University of Luxembourg; UOXF, University of Oxford.



theme from the survey was related to depression/low mood in Parkinson's (table 4).

### Potential for selection bias

Strong evidence shows that local institution related to exclusion from the study sample ( $p < 0.001$ ) where one patient from Tübingen was excluded. Inclusion rates between PwP and HCP was similar ( $p = 0.17$ ). Within PwP, there was little evidence that age ( $p = 0.08$ ), gender ( $p = 0.64$ ), disease duration ( $p = 0.76$ ), education level ( $p = 0.016$ ), living arrangements ( $p = 0.64$ ) and economic status ( $p = 0.64$ ) related to exclusion from the study sample. This suggests potential for selection bias with regard to local institution but not much evidence for other patient characteristics.

## DISCUSSION

Our study identified Q19, 'What is the best type and dose of exercise (physiotherapy) for improving muscle strength, flexibility, fitness, balance and function in people with Parkinson's?', as the most important question in the majority of analyses, as well as coming joint first in the main pooled analysis. Therefore, it was deemed the most important research question. This is the first PSP to consider the effect socioeconomic factors may have on the prioritisation of research questions. There was no substantial evidence that socioeconomic factors affected the top priority but there was an observable difference between the prioritisation of other questions in the top 10. The groups based on disease duration, educational attainment and living arrangements had the least agreement in the top 10 priorities ( $K < 60\%$ ). There were observable differences in how HCP and PwP ranked the research priorities.

### HCP versus PwP

HCP rated questions on freezing of gait and swallowing problems as more important in contrast with PwP who considered physiotherapy and improving sleep more important. Gait freeze and dysphagia symptoms are likely to have significant effects on patient's safety which could explain why HCP felt these should be included. These symptoms are more likely to be experienced later on in disease progression and not all PwP will experience them. The PwP taking part in this study were of modest disease duration (median 5 years) and thus unlikely to have reached a point in their disease where these symptoms are more common. Contrastingly, physiotherapy is currently the best treatment option for PwP for longevity of independence.<sup>32</sup> Sleep improvement could not only improve movement symptoms but reduce the fatigue experienced by an estimated 50% of PwP.<sup>33</sup>

Interestingly, the only analysis in which Q19 did not appear in the top 10 at all, was the HCP survey responses, suggesting HCP are having an impact on the prioritisation of research which does not necessarily correlate with what patients and the public prioritise. This could be due to

factors such as their knowledge of disease manifestations and treatment options, funding requirements, career paths, current research projects or personal interests. However, this misalignment could lead to less research being conducted into topics important to patients, highlighting the importance of patient and PPI in research at all stages of research methodology. It could also indicate the need to ensure that in research projects and policy development, a broader range of stakeholders should be included to ensure the preferences of HCP do not significantly overshadow that of patients. When making comparisons, it should be considered that responses between HCP and PwP will have factors influencing their responses (eg, disease duration).

### Disease duration

The disease duration quartile groups shared seven of the top 10 priorities. Reducing balance problems and falls was ranked ahead of physiotherapy by those with a disease duration of 5–9 years, this potentially correlates with the time period in which people typically begin to experience these symptoms.<sup>34</sup> This was the only group to select monitoring response to treatments, potentially correlating with the changes in medication efficacy and increasing complications as the disease progresses. Levodopa provides symptom management for most PwP; however, long-term use can have complications such as dyskinesias, impulse control disorders, motor fluctuations and reduced improvements over time.<sup>35 36</sup> Drug treatments for the different stages of Parkinson's was selected as the highest priority for those in 0–3 years disease duration category. Newly diagnosed PwP (0–3 years) may have rated this higher as they begin to notice the progression of the disease within themselves and the need to increase their Parkinson's medication. They were also the only group to select reducing tremor as a priority and not include improving sleep.

### Educational level

The distribution of scores showed a statistically significant variance depending on the educational level of responder. Moreover, only 5 of the questions in the top 10 were shared by all education groups. Level 1–2 shared five of the top questions with level 5–6 and six questions with level 7–8. In contrast, level 5–6 shared 9 of the top 10 questions with level 7–8. The level 1–2 had three priorities which did not feature in the other groups: reducing stress and anxiety, treating dyskinesias and monitoring response to treatments. Depression and anxiety are higher in low educational levels which could explain this.<sup>37</sup> People with a level 7–8 educational achievement did not have Q19 as their first priority, instead they selected drug treatments for different stages as their top priority potentially due to differences in quality of life and health literacy.<sup>38</sup> The other disparities between the groups did not necessarily have a correlation to education. Arguably, results could be biased towards those of a higher education level who may have completed the questionnaire more thoroughly.



## Living arrangements

When grouped by living arrangement, PwP shared 7 of the top 10 priorities. Those living independently wanted to know about different types of Parkinson's and the development of medications requiring fewer doses. Neither are directly related to symptom management which correlates with people living independently. The carer group prioritised monitoring dopamine levels and monitoring the response to treatments, possibly due to medication losing efficacy over time or the progression of Parkinson's.<sup>35 36</sup> The PwP needing carers or living in a care home were the only PwP to select the question pertaining to dysphagia, correlating with the previous point that these are likely experienced at later disease progression. However, despite pooling PwP supported by carers and those living in care or nursing homes, there was a small sample size (n=25); the majority of PwP were independent (n=321).

## Geography, gender and poverty status

UOXF shared 7 of the top 10 priorities with the other centres and shared Q19 as the top priority with EKUT. UL selected Q2 as their top priority; UL had the highest response from HCP (24% of participants) which could explain why the top priority for this centre was more aligned with that of HCP than the PwP analyses (EKUT 3% of responses were HCP and UOXF had 8% HCP). There was closer agreement between EKUT and UL, sharing eight of the top 10 priorities. Many UL responders were living in Germany which may explain the slightly higher rater reliability between these centres. UOXF has been working on sleep projects which has likely raised awareness within the cohort, as UOXF was the only centre to select Q6.

Nine priorities were shared across groups in both research participation and gender, and eight were shared across economic status groups: with no category changing the number one priority. Ethnicity was difficult to expand on due to 91.6% (n=217) of UOXF PwP responders being white ethnicity. The latest UK census figures<sup>39</sup> indicate that 87% of UK residents are white so this is not reflective of the UK population.

## Comparison with the 2014 Parkinson's PSP

When comparing the CENTRE-PD top 10 (n=879, 58% PwP) to the previous publication from 2014, the interim ranking round (n=475, 72% PwP) was more consistent with the updated priorities than the nominal group (n=27, 34% PwP). This could be because the group had more HCP and other professionals influencing the final decision. Q19 was unique to the CENTRE-PD top 10, indicating a change in priorities since 2014,<sup>19</sup> potentially due to recent promotions on exercise in Parkinson's. Interestingly, comparing our added questions with the original 94 question survey showed some overlap (specifically about depression, genes and apathy), questioning accuracy of the top 10 priorities list.<sup>19</sup>

Beneficially, this was an international study, but a namely limitation is that the majority of our responders with

Parkinson's were independent, white European, economically comfortable and highly educated, which does not make it a truly representative sample of the populations included. Furthermore, the 27 core questions were generated from a UK sample, querying the results validity. For future PSP groups, it might be advisable to enrol care homes, general practitioners and charities as stakeholders (with large participant databases) to encourage participant recruitment. This could enable further comparisons to be made between groups, for example, comparing responses between disability severity, and to reduce response variability between stakeholder groups (table 1). Future groups should consider the translation to more languages and distribution of the survey to a greater international audience, thanks to the ease and affordability of web-based instruments. These limitations were similar to the previous Parkinson's PSP, despite efforts from both studies to recruit from all groups of people.

## CONCLUSIONS

Overall, this study has given a useful steer as to how socioeconomic factors may influence the priorities and decision making during PSP. There was a general consensus on the top 10 across the various socioeconomic groups with the majority of groups agreeing that physiotherapy was the most important priority for PwP. This gives another avenue for future research, showing that physical activity is of very high importance to PwP, and not only does this have other health benefits, but it may be more deliverable and cheaper (compared with drug trials).

Of the socioeconomic comparisons, education level, disease duration and living arrangements, had the most impact on the prioritisation of questions. Other socioeconomic factors including poverty and gender did not significantly affect the final prioritisation.

HCP did not identify the most important priority to PwP, so care should be taken with sampling (ie, through stratification) to ensure future PSP or clinical decision groups do not miss key priorities for those living with Parkinson's, in deference to the priorities of professionals which may not always align with patient views.

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## CENTRE-PD Top 10 Supplementary Material

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Table 1. Glossary

≥7	High Importance (greater or equal to 7 in rating).
BAME	Black, Asian and Minority Ethnicity
CUREC	Central University Research Ethics Committee
EKUT	Eberhard Karls University of Tübingen
HCP	Healthcare Professionals/Researchers in Health
IQR	Interquartile Range
JLA	James Lind Alliance
K	Kappa
KW	Kruskal-Wallis
MCI	Mild Cognitive Impairment
MWW	Mann-Whitney Wilcoxon
NGT	Nominal Group Technique
NICE	National Institute of Clinical Excellence
OPDC	Oxford Parkinson's Disease Centre
PPI	Patient Public Involvement
PSP	Patient Setting Priority
PwP	People with Parkinson's
REC	Research Ethics Committee
SBC	Supported by carers/in care home
SD	Standard Deviation
UL	University of Luxembourg
UOXF	University of Oxford
WHO	World Health Organisation

## CENTRE-PD Top 10 Supplementary Material

Figure 1. Top 10 from 2014 Final Prioritisation.

**Table 3** Final prioritised and ranked uncertainties for the management of Parkinson's disease

<b>Overarching research aspiration: an effective cure for Parkinson's disease</b>	
1	What treatments are helpful for reducing balance problems and falls in people with Parkinson's?
2	What approaches are helpful for reducing stress and anxiety in people with Parkinson's?
3	What treatments are helpful for reducing dyskinesias (involuntary movements, which are a side effect of some medications) in people with Parkinson's?
4	Is it possible to identify different types of Parkinson's, eg, tremor dominant? And can we develop treatments to address these different types?
5	What best treats dementia in people with Parkinson's?
6	What best treats mild cognitive problems such as memory loss, lack of concentration, indecision and slowed thinking in people with Parkinson's?
7	What is the best method of monitoring a person with Parkinson's response to treatments?
8	What is helpful for improving the quality of sleep in people with Parkinson's?
9	What helps improve the dexterity (fine motor skills or coordination of small muscle movements) of people with Parkinson's so they can do up buttons, use computers, phones, remote controls etc?
10	What treatments are helpful in reducing urinary problems (urgency, irritable bladder, incontinence) in people with Parkinson's?



## CENTRE-PD Top 10 Supplementary Material

Figure 2. Top 26 from 2014 Interim Prioritisation

Uncertainty	PwP Score	Carer Score	F&F Score	HSCP Score	Total	Interim rank
What treatments are helpful in reducing tremor in people with Parkinson's?	93	83	92	91	359	1
What treatments are helpful for reducing balance problems and falls in people with Parkinson's?	92	93	80	94	359	1
Is it possible to identify different types of Parkinson's, eg, tremor dominant? And can we tailor treatments best according to these different types?	88	88	89	88	353	3
What treatments would ensure the medications were equally effective each day (prevented/managed wearing off, variability, on/off states) in people with Parkinson's?	89	94	88	81	352	4
Would the monitoring of dopamine levels in the body (eg, with blood tests) be helpful in determining medication timing and amount (dose)?	91	89	86	86	352	4
What is helpful for improving the quality of sleep in people with Parkinson's?	94	79.5	93	84	350.5	6
What best treats mild cognitive problems such as memory loss, lack of concentration, indecision and slowed thinking in people with Parkinson's?	87	91	77	89.5	344.5	7
What treatments are helpful in reducing urinary problems (urgency, irritable bladder, incontinence) in people with Parkinson's?	90	77	94	79	340	8
What drug treatments are best for the different stages of Parkinson's?	83	87	87	77.5	334.5	9
What approaches are helpful for reducing stress and anxiety in people with Parkinson's?	75	77	82	92	326	10
What treatments are helpful for reducing dyskinesias (involuntary movements, which are a side effect of some medications) in people with Parkinson's?	80	90	73.5	77.5	321	11
What best treats dementia in people with Parkinson's?	56	92	75	93	316	12
What interventions are effective for reducing or managing unexplained fatigue in people with Parkinson's?	78	65	85	85	313	13
What best helps prevent or reduce freezing (of gait and in general) in people with Parkinson's?	79	71.5	76	82	308.5	14
What treatments are helpful for swallowing problems (dysphagia) in people with Parkinson's?	66	74.5	81	80	301.5	15
What is the best method of monitoring a person with Parkinson's response to treatments?	81	52.5	83.5	83	300	16
What training, techniques or aids are needed for hospital staff, to make sure patients with Parkinson's get their medications correctly and on time?	53	86	64.5	89.5	293	17
What treatments are helpful in reducing bowel problems (constipation, incontinence) in people with Parkinson's?	77	85	90	40	292	18
What is the best type and dose of exercise (physiotherapy) for improving muscle strength, flexibility, fitness, balance and function in people with Parkinson's?	84	68	64.5	67.5	284	19
Can medications be developed to allow fewer doses per day for people with Parkinson's? (For example combinations of medications in one pill, slow release pills)	73	84	56	69	282	20
What helps improve dexterity (fine motor skills or coordination of small muscle movements) of people with Parkinson's so they can do up buttons, use computers, phones, remote controls etc?	85	59.5	73.5	54.5	272.5	21
What treatments are effective in reducing hallucinations (including vivid dreams) in people with Parkinson's?	52	79.5	71.5	61	264	22
What is the best treatment for stiffness (rigidity) in people with Parkinson's?	86	67	63	46	262	23
At which stage of Parkinson's is deep brain stimulation (a surgical treatment that involves implanting a 'brain pacemaker' that sends signals to specific parts of the brain) most helpful?	69	59.5	91	42	261.5	24
What training to improve knowledge and skills do informal carers (family and friends) need in order to best care for people with Parkinson's?	42	82	70	63.5	257.5	25
What is the best treatment for pain in people with Parkinson's?	82	54	60.5	57.5	254	26

F&F, family and friends; HSCP, health and social care professionals; PwP, people with Parkinson's.

## CENTRE-PD Top 10 Supplementary Material

Table 2. PSP Group Sizes

PSP Group	Year	Interim N=	Workshop N=	Note
Acne	2014	1573	43	
Eczema		493		
Vitiligo		461		
Alcohol-related Liver Disease	2017	230		
Anaesthesia and Perioperative Care	2015	1718	23	Mostly clinicians
Autism	2015	1266		
Bipolar	2016	2200	26	
Blood transfusion	2015	568	13	
Broken bones in old people	2018	209		
Carcinoma	2015	141	29	
Cellulitis	2017	353	28	
Childhood disability	2015	75	21	
Common conditions effecting hand and wrist	2017	261	21	
Contraception	2017	407	10	
Cystic Fibrosis	2017	677		
Dementia	2013	36	18	36 organisations
Depression	2016	1700	16	
Diabetes Mellitus Type 1	2011	47	23	
Diabetes Mellitus Type 2	2017	1500	26	
Hip and knee osteoarthritis	2013	266	25	
Digital Technology for Mental Health	2018	137	27	
Eczema	2012	514	40	
Emergency Medicine	2017	513	34	
Endometriosis	2017	1418	26	
Fibromyalgia	2017		18	
Head and Neck Cancer	2017	49	20	
Hidradenitis Suppurativa	2014	371	22	
Hypertension	2017	63	15	
Irritable Bowel Syndrome	2017		16	
Intensive Care Unit	2014	513		
kidney transplant	2016	256	20	
Idiopathic Intracranial Hypertension	2018	401	25	
Learning Difficulties	2017	361	25	
Lichen Sclerosis		954	29	
Life after stroke	2011	97	28	
Lyme Disease	2011	103	9	
Mesothelioma	2014	202	30	
Mild to Moderate Hearing Loss	2015	486	7	
Miscarriage	2017	2122	21	
Multiple Conditions in Later Life	2018		24	
Multiple Sclerosis	2013	669	35	
Neurodevelopmental Disorders	2017	177	31	
Neuro-oncology	2015	227	18	
Palliative and end of life care	2015	1331	24	
Parkinson's	2014	475	27	
Patient Safety in Primary Care	2017	447	22	
Pessary use for Prolapse	2017	278	23	
Physiotherapy	2018	635	27	
Pressure Ulcers	2013	141	27	
Preterm Birth	2014	537	34	
Prostate Cancer	2010		26	40 "groups" in first survey no interim data
Rare Inherited Anaemias	2018	120	31	
Scoliosis	2017	750	22	
Sight Loss and Vision	2015	664	12.9	Mean from 12 types of workshops, total 155 people
spinal cord injury	2016	293	20	
Stillbirth	2015	1118	18	Counted in photo from focus group
Stroke	2012	97	28	
Teenage and Young Adult Cancer	2018	174	25	
Tinnitus	2012	630	18	P
Urinary Incontinence	2008	11	13	11 "organisations"
Vitiligo	2010	230	47	6 observers
Womb Cancer	2016	253	23	
<b>Average (mean)</b>		<b>552</b>	<b>24</b>	
<b>Median</b>		<b>386</b>	<b>24</b>	

Data from 96 PSP groups which had published data on 24/OCT/2018

## CENTRE-PD Top 10 Supplementary Material

Table 3. Survey Responses by Participant Type and Local Institute

		Local Institute			
		UL Count	EKUT Count	UOXF Count	Total
Participant Type	PwP	116	158	237	511
	Carer/Former Carer	1	1	36	38
	Friend/Family Member	113	10	73	196
	HCP	73	7	32	112
	Person with RBD	0	0	22	22
	<b>Total</b>	<b>303</b>	<b>176</b>	<b>400</b>	<b>879</b>

Table 4. Healthcare professional responder's by role type.

Health Care Professional Role	Count
Charity Worker	1
Dietician	1
Doctor	26
Educator	1
GP	3
Laboratory / Scientist	2
Neurologist	3
Neuropsychologist	1
Not Specified	8
Nurse or Research Nurse	17
Occupational Therapist	11
PhD Student	1
Physiotherapist	10
Psychiatrist	1
Psychologist	2
Research Administrator	1
Research Assistant	1
Researcher	4
Scientific Research Project Manager	3
Social Worker	2
Speech and Language Therapist	12
Student Nurse	1
<b>Total</b>	<b>112</b>

CENTRE-PD Top 10 Supplementary Material

Figure 3. Histogram and Statistics for Duration of Disease

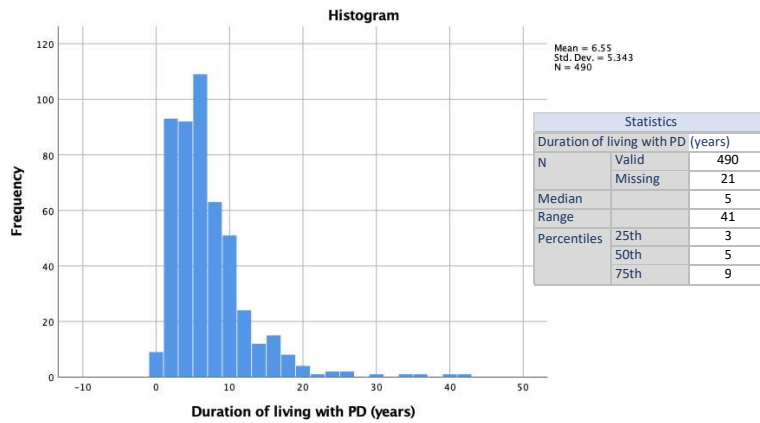
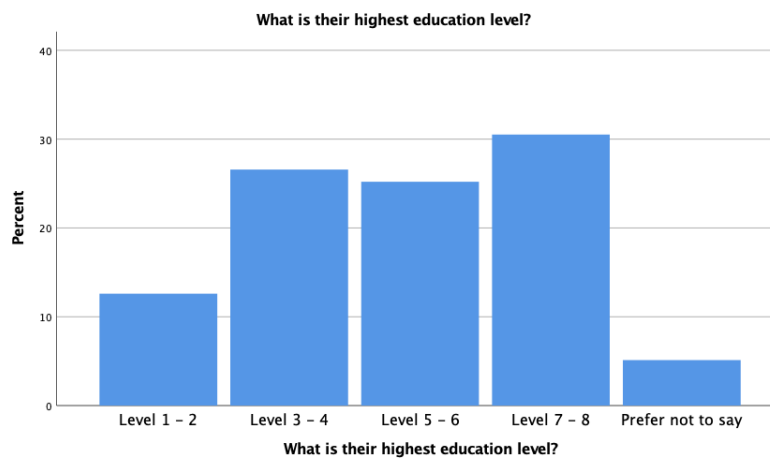


Table 5. Ethnicity Count for UOXF

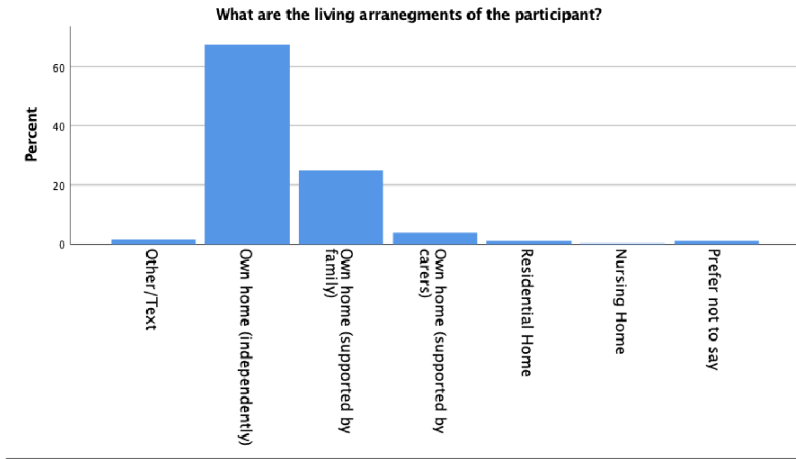
Ethnic Group	Frequency	Percent (%)
Other/Please Specify	3	1.3
Asian/Asian British	6	2.5
Arab	1	0.4
Black/Black British	3	1.3
White	217	91.6
Mixed/multiple ethnic groups	2	0.8
Prefer not to say	5	2.1
<b>Total</b>	<b>237</b>	<b>100</b>

Figure 4. Bar Chart of PwP Education Level Frequencies



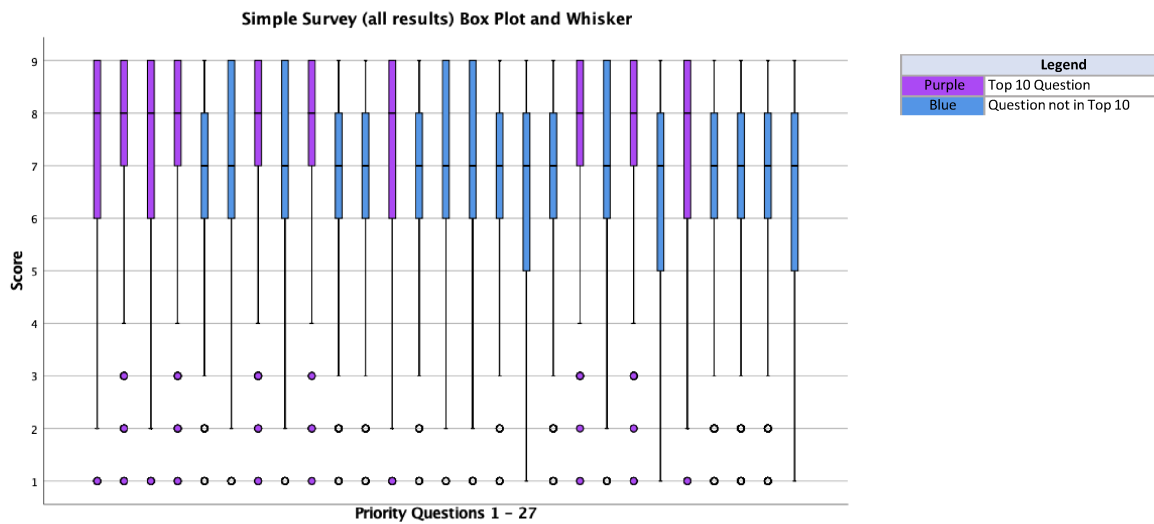
### CENTRE-PD Top 10 Supplementary Material

Figure 5. Bar Chart of PwP Living Arrangements



### Box Plot and Whiskers for Analyses

Figure 6. Box Plot and Whisker for Pooled Survey Round



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Figure 7. Box Plot and Whisker for Priority Questions by HCP and PwP

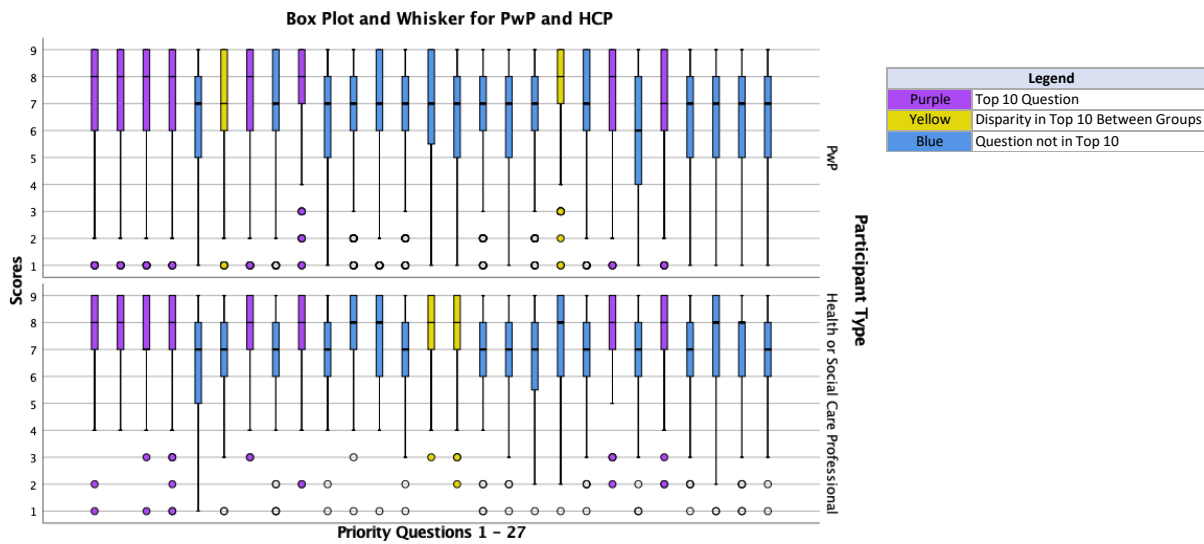
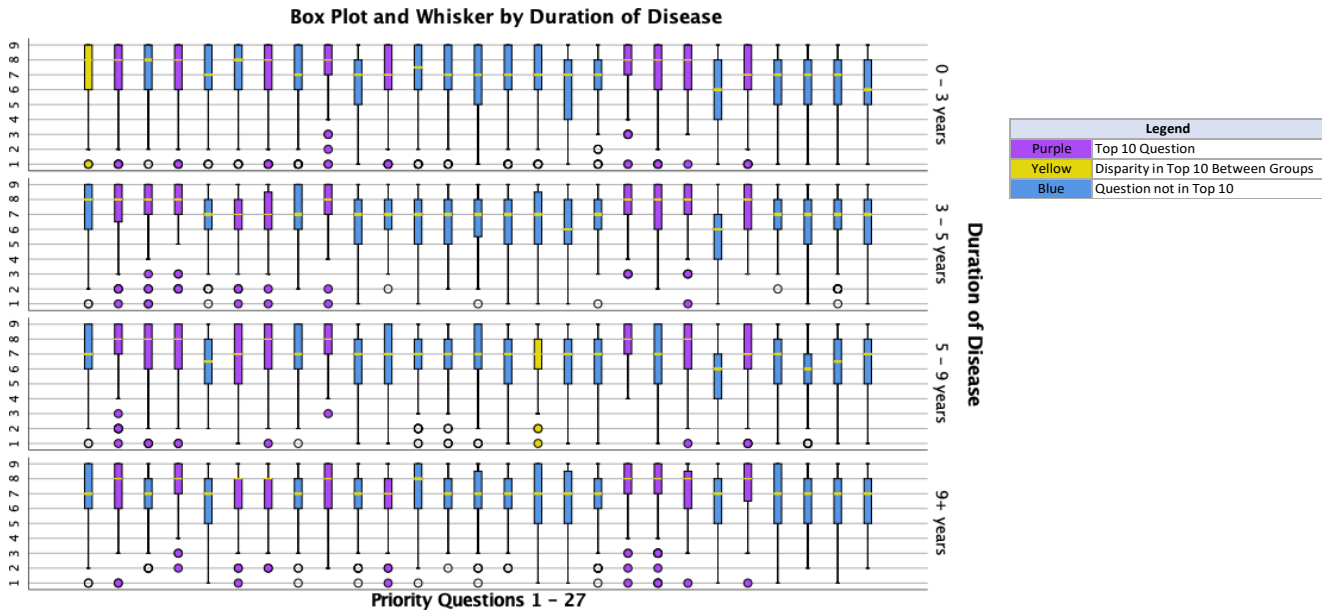


Figure 8. Box Plot and Whisker by Disease Duration



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Figure 9. Box Plot and Whisker by Education Level

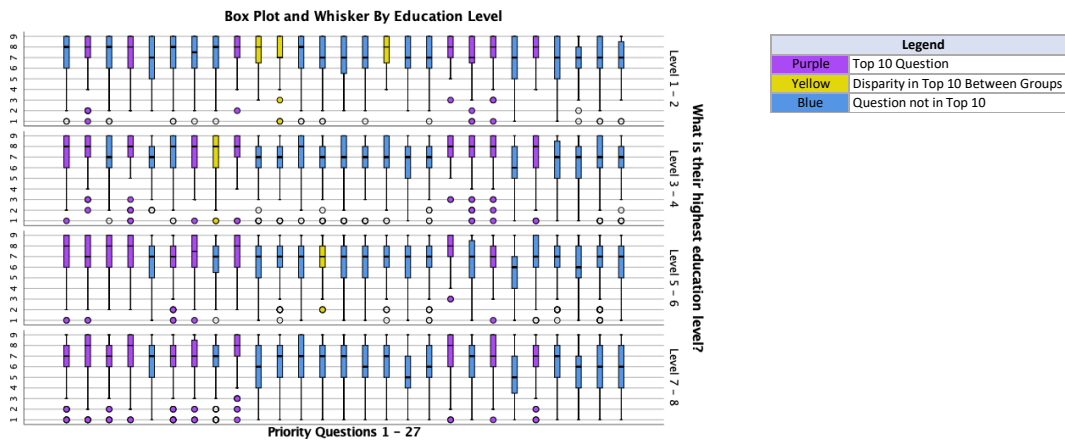
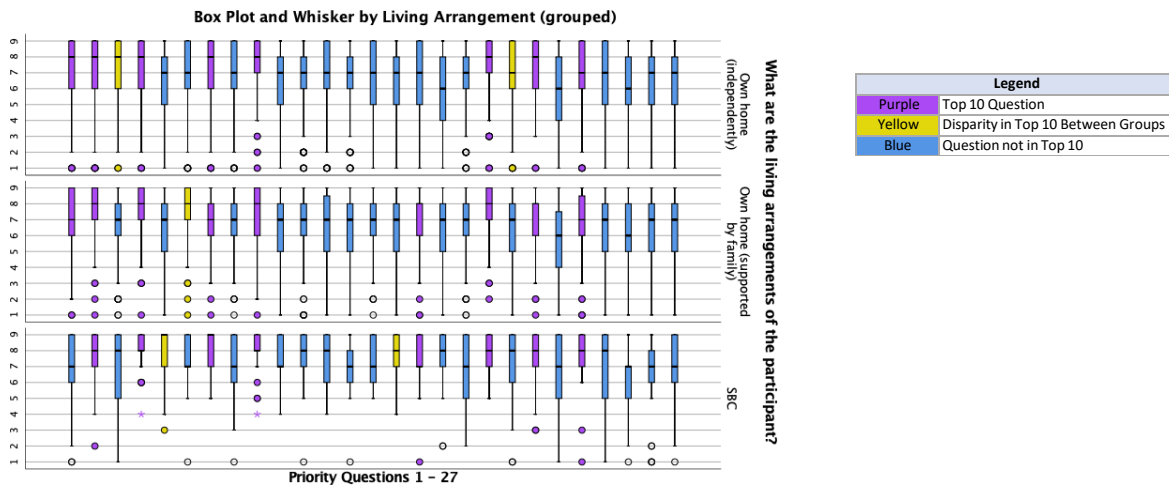


Figure 10. Box Plot and Whisker by Living Arrangements



### CENTRE-PD Top 10 Supplementary Material

Figure 11. Box Plot and Whisker of Survey Results by Local Institute

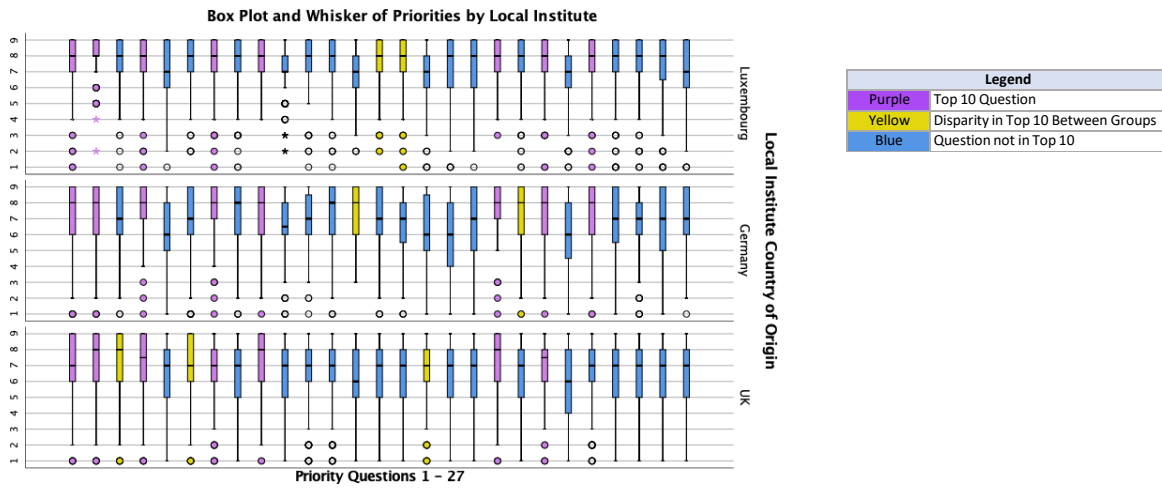
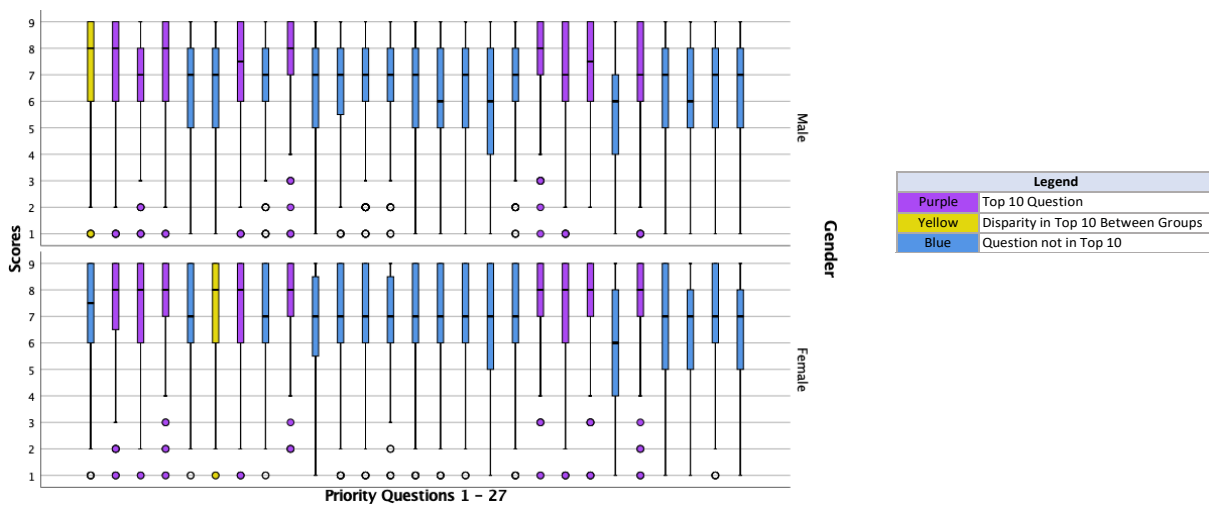


Figure 12. Box Plot and Whisker Comparing Results by Gender





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Figure 13. Box Plot and Whisker by Economic Status

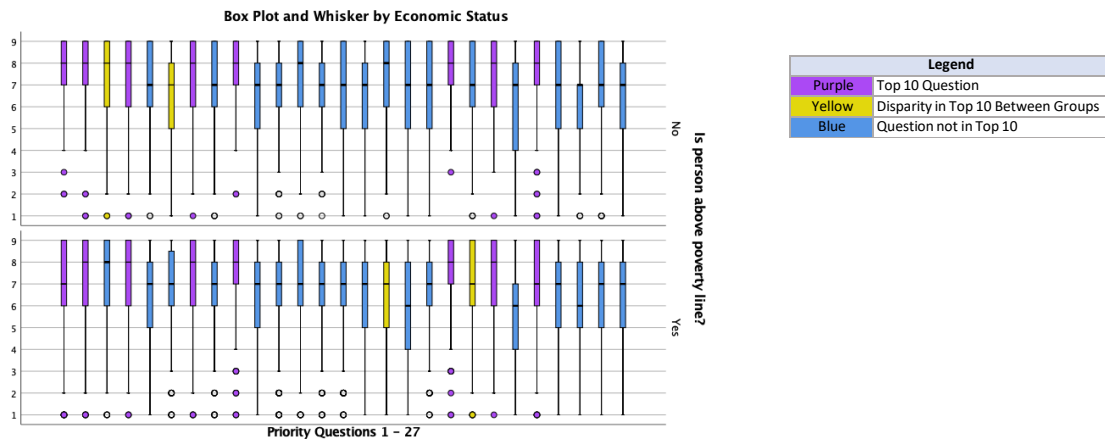
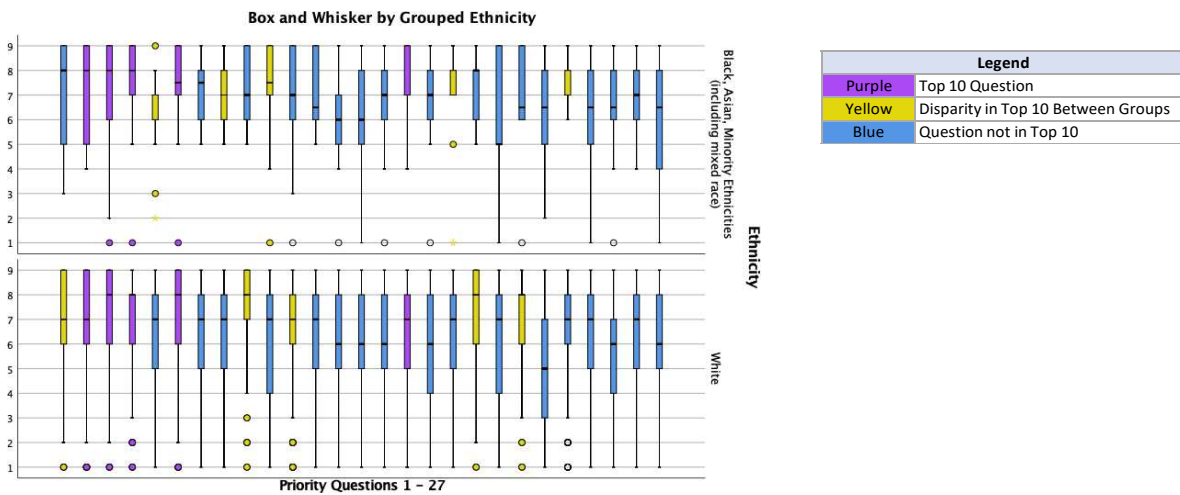


Figure 14. Box Plot and Whisker Comparing Results by Grouped Ethnicity



## CENTRE-PD Top 10 Supplementary Material

Top 10 by Sub group

Table 6. Top 10 by PwP and HCP.

Descriptive Statistics PwP and HCP								
HCP (n = 112)								
Rank	Question Number	Range		Percentiles			N who ranked ≥7	% Agreement
		Minimum	Maximum	25th	50th	75th		
1	2	4	9	7	8.5	9	99	88
2	1	1	9	7	8	9	95	85
3	7	3	9	7	8	9	95	85
4	21	2	9	7	8	9	91	81
5	4	1	9	7	8	9	89	79
6	14	3	9	7	8	9	88	79
7	15	2	9	7	8	9	88	79
8	3	1	9	7	7	9	85	76
9	9	2	9	6.75	8	9	84	75
9	23	2	9	6.75	8	9	84	75
PWP (n = 511)								
Rank	Question Number	Range		Percentiles			N who ranked ≥7	% Agreement
		Minimum	Maximum	25th	50th	75th		
1	19	1	9	7	8	9	406	79
2	9	1	9	7	8	9	394	77
3	2	1	9	6	8	9	373	73
4	4	1	9	6	8	9	371	73
5	21	1	9	6	8	9	369	72
6	7	1	9	6	8	9	358	70
7	23	1	9	6	7	9	355	69
8	1	1	9	6	8	9	348	68
9	3	1	9	6	8	9	346	68
10	6	1	9	6	7	9	346	68

## CENTRE-PD Top 10 Supplementary Material

Table 7. Top 10 by Disease Duration Quartiles

0-3 years duration (n=146)								
Rank	Question	Range		Percentiles			N who ranked ≥7	% Agreement
		Minimum	Maximum	25th	50th	75th		
1	9	1	9	7	8	9	118	80.8
2	19	1	9	7	8	9	116	79.5
3	1	1	9	7	8	9	113	77.4
4	7	1	9	7	8	9	112	76.7
5	21	2	9	6	8	9	107	73.3
6	4	1	9	6	8	9	106	72.6
7	2	1	9	6	8	9	103	70.5
8	20	1	9	6	7.5	9	101	69.2
9	23	1	9	6	7	9	101	69.2
10	11	1	9	6	7	8.75	98	67.1
3-5 years duration (n=115)								
Rank	Question	Range		Percentiles			N who ranked ≥7	% Agreement
		Minimum	Maximum	25th	50th	75th		
1	19	1	9	7	8	9	92	80.0
2	9	1	9	6	8	9	85	73.9
3	21	1	9	6	8	9	84	73.0
4	2	1	9	6	7	9	83	72.2
5	20	1	9	6	8	9	81	70.4
6	4	1	9	6	8	9	79	68.7
7	3	1	9	6	8	8.5	78	67.8
8	6	1	9	6	7	8	77	67.0
9	23	1	9	6	8	9	77	67.0
10	7	1	9	6	7	9	75	65.2
5-9 years duration (n=126)								
Rank	Question	Range		Percentiles			N who ranked ≥7	% Agreement
		Minimum	Maximum	25th	50th	75th		
1	2	1	9	7	8	9	95	75.4
1	19	3	9	7	8	9	95	75.4
3	9	1	9	6	8	9	93	73.8
4	3	1	9	6	8	9	92	73.0
5	21	1	9	6	8	8	91	72.2
6	4	1	9	6	8	9	88	69.8
7	23	1	9	6	8	9	88	69.8
8	7	1	9	6	8	8	86	68.3
9	6	1	9	6	7.5	9	86	68.3
10	16	1	9	6	7	8	82	65.1
9+ years duration (n=103)								
Rank	Question	Range		Percentiles			N who ranked ≥7	% Agreement
		Minimum	Maximum	25th	50th	75th		
1	19	3	9	7	8	9	85	82.5
2	4	3	9	7	8	9	83	80.6
3	9	2	9	7	8	9	82	79.6
4	2	1	9	6	8	9	74	71.8
5	20	1	9	6	8	9	74	71.8
6	23	1	9	6	8	9	73	70.9
7	11	1	9	6	7	8	72	69.9
8	6	1	9	6	8	8.75	71	68.9
9	21	1	9	6	7.5	9	71	68.9
10	7	2	9	6	8	8	70	68.0

## CENTRE-PD Top 10 Supplementary Material

Table 8. Top 10 by Education Level

Level 1 - 2 (n=64)								
Rank	Question	Range		Percentiles			N who	%
		Minimum	Maximum	25th	50th	75th		
1	19	3	9	7	8	9	54	84.4
2	9	2	9	7	8	9	54	84.4
3	21	1	9	7	8	9	54	84.4
4	23	4	9	7	8	9	50	78.1
5	11	1	9	7	7	9	50	78.1
6	2	1	9	7	8	9	49	76.6
7	16	4	9	6.75	8	9	48	75.0
8	10	3	9	6.75	8	9	48	75.0
9	20	1	9	6.75	7	9	48	75.0
10	4	2	9	6	8	9	47	73.4
Level 3 - 4 (n=135)								
Rank	Question	Range		Percentiles			N who ranked ≥7	% Agreement
		Minimum	Maximum	25th	50th	75th		
1	19	3	9	7	8	9	114	84.4
2	21	1	9	7	8	9	110	81.5
3	2	2	9	7	8	9	103	76.3
4	9	1	9	7	8	9	103	76.3
5	4	1	9	7	8	9	102	75.6
5	20	1	9	7	8	9	102	75.6
7	23	1	9	6	8	9	100	74.1
8	7	1	9	6	8	9	99	73.3
9	8	1	9	6	8	9	98	72.6
10	1	1	9	6	8	9	97	71.9
Level 5 - 6 (n=128)								
Rank	Question	Range		Percentiles			N who ranked ≥7	% Agreement
		Minimum	Maximum	25th	50th	75th		
1	19	3	9	7	8	9	100	78.1
2	9	2	9	6	8	9	94	73.4
3	3	2	9	6	8	9	93	72.7
4	4	2	9	6	8	9	92	71.9
5	2	1	9	6	7	9	92	71.9
6	7	1	9	6	7.5	9	90	70.3
7	1	1	9	6	8	9	84	65.6
8	6	1	9	6	7	8	84	65.6
9	21	1	9	6	7	8	82	64.1
10	13	2	9	6	7	8	80	62.5
Level 7 - 8 (n=155)								
Rank	Question	Range		Percentiles			N who ranked ≥7	% Agreement
		Minimum	Maximum	25th	50th	75th		
1	9	1	9	7	8	9	120	77.4
2	19	1	9	6	8	9	113	72.9
3	4	1	9	6	8	9	106	68.4
4	21	1	9	6	7	9	104	67.1
5	2	1	9	6	8	9	103	66.5
6	23	1	9	6	7	8	103	66.5
7	1	1	9	6	7	8	101	65.2
8	7	1	9	6	7	8.5	100	64.5
9	3	1	9	6	7	8	97	62.6
10	6	1	9	6	7	8	96	61.9

## CENTRE-PD Top 10 Supplementary Material

Table 9. Top 10 by Living Arrangements

Living at Home Independently (n=331)								
Rank	Question	Range		Percentile			N who ranked ≥7	% Agreement
		Minimum	Maximum	25th	50th	75th		
1	19	1	9	7	8	9	261	78.9
2	9	1	9	7	8	9	259	78.2
3	21	1	9	6	8	9	247	74.6
4	3	1	9	6	8	9	236	71.3
5	4	1	9	6	8	9	235	71.0
6	1	1	9	6	8	9	231	69.8
6	2	1	9	6	8	9	231	69.8
8	7	1	9	6	8	9	229	69.2
9	23	1	9	6	7	9	228	68.9
10	20	1	9	6	7	9	223	67.4
Living at Home Supported by Family (n=123)								
Rank	Question	Range		Percentile			N who ranked ≥7	% Agreement
		Minimum	Maximum	25th	50th	75th		
1	19	2	9	7	8	9	96	78.0
2	6	1	9	7	8	9	95	77.2
3	2	1	9	7	8	9	94	76.4
4	4	1	9	7	8	9	93	75.6
5	9	1	9	6	8	9	89	72.4
6	16	1	9	6	8	8	86	69.9
7	1	1	9	6	7	9	84	68.3
8	23	1	9	6	7	8.5	84	68.3
9	7	1	9	6	7	8	82	66.7
10	21	1	9	6	8	8	80	65.0
Needing Carers or in Supported Home (n=25)								
Rank	Question	Range		Percentile			N who ranked ≥7	% Agreement
		Minimum	Maximum	25th	50th	75th		
1	19	5	9	7	8	9	23	92.0
2	2	2	9	7	8	9	23	92.0
3	7	5	9	7	9	9	22	88.0
4	5	3	9	7	9	9	21	84.0
5	9	4	9	8	8	9	21	84.0
6	23	1	9	7	8	9	21	84.0
7	16	1	9	7	7	9	21	84.0
8	4	4	9	8	8	9	20	80.0
9	15	4	9	7	8	9	20	80.0

## CENTRE-PD Top 10 Supplementary Material

Table 10. Top 10 by Local Institute

UL Summary (n=303)								
Rank	Question	Range		Percentile			N who ranked ≥7	% Agreement
		Minimum	Maximum	25th	50th	75th		
1	2	2	9	8	8	9	275	90.8
2	9	4	9	7	8	9	268	88.4
3	1	1	9	7	8	9	266	87.8
4	4	1	9	7	8	9	263	86.8
5	7	1	9	7	8	9	258	85.1
6	19	3	9	7	8	9	257	84.8
7	21	1	9	7	8	9	253	83.5
7	23	1	9	7	8	9	253	83.5
9	15	1	9	7	8	9	250	82.5
10	14	2	9	7	8	9	247	81.5
EKUT Summary (n=176)								
Rank	Question	Range		Percentile			N who ranked ≥7	% Agreement
		Minimum	Maximum	25th	50th	75th		
1	19	1	9	7	8	9	141	80.1
2	4	1	9	7	8	9	134	76.1
3	7	1	9	7	8	9	133	75.6
4	9	1	9	6	8	9	130	73.9
5	21	1	9	6	8	9	127	72.2
5	23	1	9	6	8	9	127	72.2
7	20	1	9	6	8	9	126	71.6
8	2	1	9	6	8	9	124	70.5
9	13	2	9	6	8	9	122	69.3
10	1	1	9	6	8	9	114	64.8
UOXF Summary (n=400)								
Rank	Question	Range		Percentile			N who ranked ≥7	% Agreement
		Minimum	Maximum	25th	50th	75th		
1	19	1	9	6	8	9	297	74.3
1	9	1	9	6	8	9	297	74.3
3	21	1	9	6	7.5	8	293	73.3
4	2	1	9	6	8	9	291	72.8
5	3	1	9	6	8	9	274	68.5
6	6	1	9	6	7	9	274	68.5
7	7	1	9	6	7	8	271	67.8
8	4	1	9	6	7.5	9	270	67.5
9	16	1	9	6	7	8	268	67.0
10	1	1	9	6	7	9	265	66.3

## CENTRE-PD Top 10 Supplementary Material

Table 11. Top 10 Priorities by Gender

Male (n=312)								
Rank	Question Number	Range		Percentiles			N who ranked ≥7	% Agreement
		Minimum	Maximum	25th	50th (Median)	75th		
1	19	1	9	7	8	9	246	78.8
2	9	1	9	7	8	9	236	75.6
3	2	1	9	6	8	9	224	71.8
4	1	1	9	6	8	9	218	69.9
5	4	1	9	6	8	9	217	69.6
6	7	1	9	6	7.5	9	216	69.2
7	21	1	9	6	7.5	9	212	67.9
8	3	1	9	6	7	8	207	66.3
9	23	1	9	6	7	9	204	65.4
10	20	1	9	6	7	9	203	65.1

Female (n=192)								
Rank	Question Number	Range		Percentiles			N who ranked ≥7	% Agreement
		Minimum	Maximum	25th	50th (Median)	75th		
1	19	1	9	7	8	9	156	81.3
2	9	1	9	7	8	9	153	79.7
3	21	1	9	7	8	9	151	78.6
4	23	1	9	7	8	9	148	77.1
5	4	1	9	7	8	9	147	76.6
6	2	1	9	6.75	8	9	144	75.0
7	6	1	9	6	8	9	143	74.5
8	7	1	9	6	8	9	137	71.4
9	3	1	9	6	8	9	134	69.8
10	20	1	9	6	8	9	134	69.8

## CENTRE-PD Top 10 Supplementary Material

Table 12. Top 10 by Economic Status

Above Poverty Line (n=372)								
Rank	Question	Range		Percentile			N who ranked ≥7	% Agreement
		Minimum	Maximum	25th	50th	75th		
1	19	1	9	7	8	9	291	78.2
2	9	1	9	7	8	9	287	77.2
3	4	1	9	6	8	9	272	73.1
4	21	1	9	6	8	9	268	72.0
5	2	1	9	6	8	9	263	70.7
6	3	1	9	6	8	9	255	68.5
6	7	1	9	6	8	9	255	68.5
8	6	1	9	6	7	8.25	252	67.7
9	23	1	9	6	7	9	248	66.7
10	1	1	9	6	7	9	247	66.4

Below Poverty Line (n=73)								
Rank	Question	Range		Percentile			N who ranked ≥7	% Agreement
		Minimum	Maximum	25th	50th	75th		
1	19	3	9	7	8	9	65	89.0
2	2	1	9	7	8	9	60	82.2
3	9	2	9	7	8	9	58	79.5
4	1	2	9	7	8	9	55	75.3
5	23	1	9	7	8	9	55	75.3
6	7	1	9	6	8	9	53	72.6
6	21	1	9	6	8	9	53	72.6
8	20	1	9	6	7	9	53	72.6
9	16	1	9	6	8	9	52	71.2
10	4	1	9	6	8	9	51	69.9

Table 13. Top 10 by Ethnicity Groups

BAME (n=11)								
Rank	Question	Range		Percentiles			N who ranked ≥7	% Agreement
		Minimum	Maximum	25th	50th	75th		
1	6	1	9	5	8	9	10	90.9
2	4	1	9	5	8	9	9	81.8
3	18	1	9	5	8	9	9	81.8
4	3	1	9	5	8	9	8	72.7
5	5	3	9	5	8	9	8	72.7
6	10	1	9	5	8	9	8	72.7
7	16	4	9	5	8	9	8	72.7
8	23	6	9	5	8	9	8	72.7
9	2	4	9	5	8	9	7	63.6
10	8	5	9	5	8	9	7	63.6

White (n=217)								
Rank	Question	Range		Percentiles			N who ranked ≥7	% Agreement
		Minimum	Maximum	25th	50th	75th		
1	9	1	9	7	8	9	163	75.1
2	19	1	9	6	8	9	162	74.7
3	21	1	9	6	8	8	153	70.5
4	6	1	9	6	8	9	152	70.0
5	2	1	9	6	7	9	149	68.7
6	3	1	9	6	8	9	146	67.3
7	4	1	9	6	8	8	141	65.0
8	1	1	9	6	7	9	140	64.5
9	16	1	9	5	7	8	137	63.1
10	11	1	9	6	7	8	133	61.3



## CENTRE-PD Top 10 Supplementary Material

## Kappa Tables

Table 14. Kappa Agreement between Disease Duration Groups

Symmetric Measures				
Comparison	Kappa Value	Asymptotic Standard Error <i>a</i>	Approximate T <i>b</i>	Approximate Significance
0-3 years vs 3-5 years	0.682	0.146	3.546	0.000
0-3 years v 5-9 years	0.524	0.170	2.720	0.007
0-3 years v 9+ years	0.841	0.108	4.371	0.000
3-5 years v 5-9 years	0.841	0.108	4.371	0.000
3-5 years v 9+ years	0.841	0.108	4.371	0.000
5-9 years v 9+ years	0.682	0.146	3.546	0.000

*a* Not assuming the null hypothesis.  
*b* Using the asymptotic standard error assuming the null hypothesis.

Table 15. Kappa Agreement between Education Levels

Symmetric Measures				
Comparison	Kappa	Asymptotic Standard Error <i>a</i>	Approximate T <i>b</i>	Approximate Significance
Level 1 - 2 vs Level 3 - 4	0.524	0.170	2.720	0.007
Level 1 - 2 vs Level 5 - 6	0.206	0.192	1.070	0.285
Level 1 - 2 vs Level 7 - 8	0.365	0.185	1.895	0.058
Level 3 - 4 vs Level 5 - 6	0.524	0.170	2.720	0.007
Level 3 - 4 vs Level 7 - 8	0.682	0.146	3.546	0.000
Level 5 - 6 vs Level 7 - 8	0.841	0.108	4.371	0.000

*a* Not assuming the null hypothesis.  
*b* Using the asymptotic standard error assuming the null hypothesis.

Table 16. Kappa test of Agreement by Living Arrangement (grouped)

Symmetric Measures				
Comparison	Kappa	Asymptotic Standard Error <i>a</i>	Approximate T <i>b</i>	Approximate Significance
Independently vs Supported by Family	0.682	0.146	3.546	0.000
Independently vs Carers/Supported Home	0.524	0.170	2.720	0.007
Supported by Family vs Carers/Supported Home	0.682	0.146	3.546	0.000
N of Valid Cases	27			

*a* Not assuming the null hypothesis.  
*b* Using the asymptotic standard error assuming the null hypothesis.

Table 17. Kappa Test for Agreement between Local Institutes

Measure of Agreement				
Comparison	Kappa	Asymptotic Standard Error <i>a</i>	Approximate T <i>b</i>	Approximate Significance
UL * EKUT	0.682	0.146	3.546	0
UL * UOXF	0.524	0.17	2.72	0.007
EKUT * UOXF	0.524	0.17	2.72	0.007

*a* Not assuming the null hypothesis.  
*b* Using the asymptotic standard error assuming the null hypothesis.

## CENTRE-PD Top 10 Supplementary Material

Table 18. Kappa for Gender

		Symmetric Measures			
		Value	Asymptotic Standard Error <sup>a</sup>	Approximate T <sup>b</sup>	Approximate Significance
Measure of Agreement	Kappa	.841	.108	4.371	.000
N of Valid Cases		27			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Table 19. Kappa for Economic Status

		Symmetric Measures			
		Value	Asymptotic Standard Error <sup>a</sup>	Approximate T <sup>b</sup>	Approximate Significance
Measure of Agreement	Kappa	.682	.146	3.546	.000
N of Valid Cases		27			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Table 20. Kappa test between HCP and PWP

		Symmetric Measures			
		Value	Asymptotic Standard Error <sup>a</sup>	Approximate T <sup>b</sup>	Approximate Significance
Measure of Agreement	Kappa	.682	.146	3.546	.000
N of Valid Cases		27			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Table 21. Kappa test with Deane et al Top 10 by Focus group

		Symmetric Measures			
		Value	Asymptotic Standard Error <sup>a</sup>	Approximate T <sup>b</sup>	Approximate Significance
Measure of Agreement	Kappa	.206	.192	1.070	.285
N of Valid Cases		27			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

## CENTRE-PD Top 10 Supplementary Material

Table 22. Kappa test with Deane et al by interim ranking

<b>Symmetric Measures</b>					
		Value	Asymptotic Standard Error <sup>a</sup>	Approximate T <sup>b</sup>	Approximate Significance
Measure of Agreement	Kappa	.524	.170	2.720	.007
N of Valid Cases		27			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

## CENTRE-PD Top 10 Supplementary Material

## Distribution Analyses

Table 23. Distribution Comparisons of each question by subgroup

Question Number	Question	Significance (p-value)						
		HCP vs PwP (MWW)	Disease Duration (KW)	Education Level (KW)	Living Arrangements (KW)	Local Institute (KW)	Gender (MWW)	Economic Status (MWW)
1	What treatments are helpful in reducing tremor in people with Parkinson's?	0.001	0.305	0.027	0.591	0.000	0.960	0.113
2	What treatments are helpful for reducing balance problems and falls in people with Parkinson's?	0.000	0.995	0.043	0.088	0.000	0.120	0.268
3	Is it possible to identify different types of Parkinson's, e.g., tremor dominant? And can we tailor treatments best according to these different types?	0.794	0.087	0.403	0.321	0.079	0.027	0.888
4	What treatments would ensure the medications were equally effective each day (prevented/managed wearing off, variability, on/off states) in people with Parkinson's?	0.275	0.040	0.752	0.186	0.000	0.023	0.907
5	Would the monitoring of dopamine levels in the body (e.g., with blood tests) be helpful in determining medication timing and amount (dose)?	0.084	0.156	0.161	0.001	0.000	0.022	0.043
6	What is helpful for improving the quality of sleep in people with Parkinson's?	0.703	0.987	0.009	0.212	0.035	0.001	0.154

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<b>7</b>	What best treats mild cognitive problems such as memory loss, lack of concentration, indecision and slowed thinking in people with Parkinson's?	0.091	0.300	0.502	0.012	0.000	0.174	0.499
<b>8</b>	What treatments are helpful in reducing urinary problems (urgency, irritable bladder, incontinence) in people with Parkinson's?	0.592	0.953	0.011	0.825	0.000	0.413	0.950
<b>9</b>	What drug treatments are best for the different stages of Parkinson's?	0.248	0.728	0.529	0.059	0.001	0.201	0.756
<b>10</b>	What approaches are helpful for reducing stress and anxiety in people with Parkinson's?	0.008	0.387	0.000	0.097	0.000	0.008	0.288
<b>11</b>	What treatments are helpful for reducing dyskinesias (involuntary movements, which are a side effect of some medications) in people with Parkinson's?	0.015	0.653	0.004	0.079	0.000	0.001	0.426
<b>12</b>	What best treats dementia in people with Parkinson's?	0.041	0.103	0.027	0.249	0.000	0.106	0.122
<b>13</b>	What interventions are effective for reducing or managing unexplained fatigue in people with Parkinson's?	0.285	0.502	0.180	0.356	0.000	0.887	0.932
<b>14</b>	What best helps prevent or reduce freezing (of gait and in general) in people with Parkinson's?	0.002	0.411	0.067	0.402	0.000	0.049	0.322

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<b>15</b>	What treatments are helpful for swallowing problems (dysphagia) in people with Parkinson's?	0.000	0.331	0.009	0.043	0.000	0.014	0.934
<b>16</b>	What is the best method of monitoring a person with Parkinson's response to treatments?	0.602	0.629	0.000	0.053	0.004	0.189	0.034
<b>17</b>	What training, techniques or aids are needed for hospital staff, to make sure patients with Parkinson's get their medications correctly and on time?	0.007	0.603	0.000	0.002	0.000	0.001	0.090
<b>18</b>	What treatments are helpful in reducing bowel problems (constipation, incontinence) in people with Parkinson's?	0.224	0.650	0.000	0.468	0.000	0.125	0.411
<b>19</b>	What is the best type and dose of exercise (physiotherapy) for improving muscle strength, flexibility, fitness, balance and function in people with Parkinson's?	0.072	0.439	0.026	0.439	0.000	0.166	0.687
<b>20</b>	Can medications be developed to allow fewer doses per day for people with Parkinson's? (For example combinations of medications in one pill, slow release pills)	0.347	0.106	0.000	0.071	0.000	0.221	0.273
<b>21</b>	What helps improve the dexterity (fine motor skills or coordination of small muscle movements) of people with Parkinson's so they can do up buttons, use computers, phones, remote controls etc?	0.337	0.739	0.009	0.066	0.004	0.005	0.540
<b>22</b>	What treatments are effective in reducing hallucinations (including vivid dreams) in people with Parkinson's?	0.000	0.170	0.000	0.322	0.000	0.225	0.379

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<b>23</b>	What is the best treatment for stiffness (rigidity) in people with Parkinson's?	0.185	0.680	0.033	0.137	0.000	0.016	0.083
<b>24</b>	At which stage of Parkinson's is deep brain stimulation (a surgical treatment that involves implanting a 'brain pacemaker' that sends signals to specific parts of the brain) most helpful?	0.423	0.691	0.383	0.090	0.000	0.853	0.152
<b>25</b>	What training to improve knowledge and skills do informal carers (family and friends) need in order to best care for people with Parkinson's?	0.000	0.417	0.000	0.884	0.000	0.297	0.467
<b>26</b>	What is the best treatment for pain in people with Parkinson's?	0.020	0.258	0.002	0.827	0.000	0.001	0.116
<b>27</b>	What speech therapy techniques are helpful for communication problems in people with Parkinson's?	0.001	0.731	0.001	0.337	0.000	0.421	0.813

## CENTRE-PD Top 10 Supplementary Material

Table 24. Pairwise comparison of significant KW Disease Duration for Question 4.

**Pairwise Comparisons of Duration of Disease**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
0 - 3 years-5 - 9 years	-1.548	16.698	-.093	.926	1.000
0 - 3 years-3 - 5 years	-19.389	17.121	-1.132	.257	1.000
0 - 3 years-9+ years	-46.026	17.671	-2.605	.009	.055
5 - 9 years-3 - 5 years	17.841	17.710	1.007	.314	1.000
5 - 9 years-9+ years	-44.478	18.241	-2.438	.015	.089
3 - 5 years-9+ years	-26.638	18.630	-1.430	.153	.917

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 25. Pairwise comparison of significant KW Education Level for Question 1.

**Pairwise Comparisons of What is their highest education level?**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
Level 7 - 8-Level 5 - 6	33.346	16.224	2.055	.040	.239
Level 7 - 8-Level 1 - 2	42.944	20.184	2.128	.033	.200
Level 7 - 8-Level 3 - 4	43.192	15.992	2.701	.007	.041
Level 5 - 6-Level 1 - 2	9.598	20.796	.462	.644	1.000
Level 5 - 6-Level 3 - 4	9.846	16.759	.587	.557	1.000
Level 1 - 2-Level 3 - 4	-.248	20.616	-.012	.990	1.000

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 26. Pairwise comparison of significant KW Education Level for Question 2.

**Pairwise Comparisons of What is their highest education level?**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
Level 7 - 8-Level 5 - 6	9.144	16.210	.564	.573	1.000
Level 7 - 8-Level 3 - 4	34.072	15.978	2.132	.033	.198
Level 7 - 8-Level 1 - 2	47.371	20.166	2.349	.019	.113
Level 5 - 6-Level 3 - 4	24.928	16.744	1.489	.137	.819
Level 5 - 6-Level 1 - 2	38.227	20.779	1.840	.066	.395
Level 3 - 4-Level 1 - 2	13.298	20.598	.646	.519	1.000

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 27. Pairwise comparison of significant KW Education Level for Question 6.

**Pairwise Comparisons of What is their highest education level?**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
Level 7 - 8-Level 5 - 6	15.056	16.313	.923	.356	1.000
Level 7 - 8-Level 3 - 4	45.459	16.079	2.827	.005	.028
Level 7 - 8-Level 1 - 2	52.903	20.294	2.607	.009	.055
Level 5 - 6-Level 3 - 4	30.403	16.850	1.804	.071	.427
Level 5 - 6-Level 1 - 2	37.848	20.910	1.810	.070	.422
Level 3 - 4-Level 1 - 2	7.445	20.729	.359	.719	1.000

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.



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Table 28. Pairwise comparison of significant KW Education Level for Question 8.

**Pairwise Comparisons of What is their highest education level?**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
Level 5 - 6-Level 7 - 8	-5.576	16.338	-.341	.733	1.000
Level 5 - 6-Level 1 - 2	41.242	20.943	1.969	.049	.294
Level 5 - 6-Level 3 - 4	46.542	16.877	2.758	.006	.035
Level 7 - 8-Level 1 - 2	35.667	20.326	1.755	.079	.476
Level 7 - 8-Level 3 - 4	40.966	16.104	2.544	.011	.066
Level 1 - 2-Level 3 - 4	-5.300	20.761	-.255	.799	1.000

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 29. Pairwise comparison of significant KW Education Level for Question 10.

**Pairwise Comparisons of What is their highest education level?**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
Level 7 - 8-Level 5 - 6	26.177	16.431	1.593	.111	.667
Level 7 - 8-Level 3 - 4	44.349	16.196	2.738	.006	.037
Level 7 - 8-Level 1 - 2	88.634	20.441	4.336	.000	.000
Level 5 - 6-Level 3 - 4	18.172	16.972	1.071	.284	1.000
Level 5 - 6-Level 1 - 2	62.457	21.062	2.965	.003	.018
Level 3 - 4-Level 1 - 2	44.285	20.879	2.121	.034	.204

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 30. Pairwise comparison of significant KW Education Level for Question 11.

**Pairwise Comparisons of What is their highest education level?**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
Level 7 - 8-Level 5 - 6	20.802	16.359	1.272	.204	1.000
Level 7 - 8-Level 3 - 4	48.662	16.126	3.018	.003	.015
Level 7 - 8-Level 1 - 2	59.869	20.352	2.942	.003	.020
Level 5 - 6-Level 3 - 4	27.860	16.899	1.649	.099	.595
Level 5 - 6-Level 1 - 2	39.066	20.970	1.863	.062	.375
Level 3 - 4-Level 1 - 2	11.206	20.788	.539	.590	1.000

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 31. Pairwise comparison of significant KW Education Level for Question 12.

**Pairwise Comparisons of What is their highest education level?**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
Level 5 - 6-Level 7 - 8	-20.583	16.349	-1.259	.208	1.000
Level 5 - 6-Level 3 - 4	43.937	16.888	2.602	.009	.056
Level 5 - 6-Level 1 - 2	50.020	20.956	2.387	.017	.102
Level 7 - 8-Level 3 - 4	23.354	16.115	1.449	.147	.884
Level 7 - 8-Level 1 - 2	29.437	20.339	1.447	.148	.887
Level 3 - 4-Level 1 - 2	6.083	20.775	.293	.770	1.000

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

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Table 32. Pairwise comparison of significant KW Education Level for Question 15.

**Pairwise Comparisons of What is their highest education level?**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
Level 7 - 8-Level 5 - 6	15.901	16.422	.968	.333	1.000
Level 7 - 8-Level 3 - 4	43.749	16.187	2.703	.007	.041
Level 7 - 8-Level 1 - 2	56.421	20.430	2.762	.006	.035
Level 5 - 6-Level 3 - 4	27.848	16.963	1.642	.101	.604
Level 5 - 6-Level 1 - 2	40.520	21.051	1.925	.054	.325
Level 3 - 4-Level 1 - 2	12.672	20.868	.607	.544	1.000

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 33. Pairwise comparison of significant KW Education Level for Question 16.

**Pairwise Comparisons of What is their highest education level?**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
Level 7 - 8-Level 5 - 6	18.679	16.379	1.140	.254	1.000
Level 7 - 8-Level 3 - 4	41.464	16.145	2.568	.010	.061
Level 7 - 8-Level 1 - 2	81.487	20.376	3.999	.000	.000
Level 5 - 6-Level 3 - 4	22.785	16.919	1.347	.178	1.000
Level 5 - 6-Level 1 - 2	62.809	20.995	2.992	.003	.017
Level 3 - 4-Level 1 - 2	40.023	20.813	1.923	.054	.327

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 34. Pairwise comparison of significant KW Education Level for Question 17.

**Pairwise Comparisons of What is their highest education level?**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
Level 7 - 8-Level 5 - 6	54.895	16.464	3.334	.001	.005
Level 7 - 8-Level 3 - 4	68.367	16.229	4.213	.000	.000
Level 7 - 8-Level 1 - 2	98.266	20.483	4.798	.000	.000
Level 5 - 6-Level 3 - 4	13.471	17.007	.792	.428	1.000
Level 5 - 6-Level 1 - 2	43.371	21.104	2.055	.040	.239
Level 3 - 4-Level 1 - 2	29.900	20.921	1.429	.153	.918

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 35. Pairwise comparison of significant KW Education Level for Question 18.

**Pairwise Comparisons of What is their highest education level?**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
Level 7 - 8-Level 5 - 6	41.617	16.381	2.541	.011	.066
Level 7 - 8-Level 3 - 4	53.936	16.147	3.340	.001	.005
Level 7 - 8-Level 1 - 2	76.063	20.379	3.732	.000	.001
Level 5 - 6-Level 3 - 4	12.318	16.921	.728	.467	1.000
Level 5 - 6-Level 1 - 2	34.445	20.998	1.640	.101	.605
Level 3 - 4-Level 1 - 2	22.127	20.815	1.063	.288	1.000

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

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Table 36. Pairwise comparison of significant KW Education Level for Question 19.

**Pairwise Comparisons of What is their highest education level?**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
Level 7 - 8-Level 1 - 2	34.781	19.958	1.743	.081	.488
Level 7 - 8-Level 5 - 6	39.973	16.042	2.492	.013	.076
Level 7 - 8-Level 3 - 4	41.481	15.813	2.623	.009	.052
Level 1 - 2-Level 5 - 6	-5.191	20.563	-.252	.801	1.000
Level 1 - 2-Level 3 - 4	-6.700	20.385	-.329	.742	1.000
Level 5 - 6-Level 3 - 4	1.509	16.571	.091	.927	1.000

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 37. Pairwise comparison of significant KW Education Level for Question 20.

**Pairwise Comparisons of What is their highest education level?**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
Level 7 - 8-Level 5 - 6	9.380	16.279	.576	.564	1.000
Level 7 - 8-Level 1 - 2	46.493	20.253	2.296	.022	.130
Level 7 - 8-Level 3 - 4	61.676	16.047	3.844	.000	.001
Level 5 - 6-Level 1 - 2	37.113	20.868	1.779	.075	.452
Level 5 - 6-Level 3 - 4	52.296	16.816	3.110	.002	.011
Level 1 - 2-Level 3 - 4	-15.182	20.686	-.734	.463	1.000

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 38. Pairwise comparison of significant KW Education Level for Question 21.

**Pairwise Comparisons of What is their highest education level?**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
Level 5 - 6-Level 7 - 8	-3.987	16.228	-.246	.806	1.000
Level 5 - 6-Level 3 - 4	40.673	16.762	2.426	.015	.091
Level 5 - 6-Level 1 - 2	52.379	20.801	2.518	.012	.071
Level 7 - 8-Level 3 - 4	36.686	15.995	2.294	.022	.131
Level 7 - 8-Level 1 - 2	48.392	20.188	2.397	.017	.099
Level 3 - 4-Level 1 - 2	11.706	20.621	.568	.570	1.000

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 39. Pairwise comparison of significant KW Education Level for Question 22.

**Pairwise Comparisons of What is their highest education level?**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
Level 7 - 8-Level 5 - 6	8.198	16.498	.497	.619	1.000
Level 7 - 8-Level 3 - 4	48.578	16.263	2.987	.003	.017
Level 7 - 8-Level 1 - 2	82.558	20.525	4.022	.000	.000
Level 5 - 6-Level 3 - 4	40.380	17.042	2.369	.018	.107
Level 5 - 6-Level 1 - 2	74.359	21.148	3.516	.000	.003
Level 3 - 4-Level 1 - 2	33.979	20.965	1.621	.105	.630

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

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Table 40. Pairwise comparison of significant KW Education Level for Question 23.

**Pairwise Comparisons of What is their highest education level?**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
Level 5 - 6-Level 7 - 8	-2.274	16.275	-.140	.889	1.000
Level 5 - 6-Level 3 - 4	23.389	16.811	1.391	.164	.985
Level 5 - 6-Level 1 - 2	54.359	20.862	2.606	.009	.055
Level 7 - 8-Level 3 - 4	21.115	16.042	1.316	.188	1.000
Level 7 - 8-Level 1 - 2	52.085	20.247	2.572	.010	.061
Level 3 - 4-Level 1 - 2	30.970	20.681	1.498	.134	.805

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 41. Pairwise comparison of significant KW Education Level for Question 25.

**Pairwise Comparisons of What is their highest education level?**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
Level 7 - 8-Level 5 - 6	39.761	16.439	2.419	.016	.093
Level 7 - 8-Level 3 - 4	65.627	16.204	4.050	.000	.000
Level 7 - 8-Level 1 - 2	69.667	20.451	3.406	.001	.004
Level 5 - 6-Level 3 - 4	25.867	16.981	1.523	.128	.766
Level 5 - 6-Level 1 - 2	29.906	21.072	1.419	.156	.935
Level 3 - 4-Level 1 - 2	4.040	20.889	.193	.847	1.000

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 42. Pairwise comparison of significant KW Education Level for Question 26.

**Pairwise Comparisons of What is their highest education level?**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
Level 7 - 8-Level 5 - 6	20.230	16.419	1.232	.218	1.000
Level 7 - 8-Level 3 - 4	53.546	16.184	3.309	.001	.006
Level 7 - 8-Level 1 - 2	57.199	20.426	2.800	.005	.031
Level 5 - 6-Level 3 - 4	33.316	16.960	1.964	.049	.297
Level 5 - 6-Level 1 - 2	36.969	21.046	1.757	.079	.474
Level 3 - 4-Level 1 - 2	3.653	20.863	.175	.861	1.000

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 43. Pairwise comparison of significant KW Education Level for Question 27.

**Pairwise Comparisons of What is their highest education level?**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
Level 7 - 8-Level 5 - 6	27.543	16.440	1.675	.094	.563
Level 7 - 8-Level 3 - 4	51.247	16.205	3.162	.002	.009
Level 7 - 8-Level 1 - 2	71.110	20.453	3.477	.001	.003
Level 5 - 6-Level 3 - 4	23.703	16.982	1.396	.163	.977
Level 5 - 6-Level 1 - 2	43.566	21.074	2.067	.039	.232
Level 3 - 4-Level 1 - 2	19.863	20.891	.951	.342	1.000

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

## CENTRE-PD Top 10 Supplementary Material

Table 44. Pairwise comparison of significant KW Living Arrangements for Question 5.

**Pairwise Comparisons of What are the living arrangements of the participant?**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
Own home (independently)-Own home (supported by family)	-3.475	14.416	-.241	.810	1.000
Own home (independently)-SBC	-106.575	28.316	-3.764	.000	.001
Own home (supported by family)-SBC	-103.100	29.950	-3.442	.001	.002

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple ...

Table 45. Pairwise comparison of significant KW Living Arrangements for Question 7.

**Pairwise Comparisons of What are the living arrangements of the participant?**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
Own home (supported by family)-Own home (independently)	21.187	14.291	1.483	.138	.415
Own home (supported by family)-SBC	-86.875	29.690	-2.926	.003	.010
Own home (independently)-SBC	-65.688	28.070	-2.340	.019	.058

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple ...

Table 46. Pairwise comparison of significant KW Living Arrangements for Question 15.

**Pairwise Comparisons of What are the living arrangements of the participant?**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
Own home (independently)-Own home (supported by family)	-2.566	14.429	-.178	.859	1.000
Own home (independently)-SBC	-70.963	28.341	-2.504	.012	.037
Own home (supported by family)-SBC	-68.397	29.977	-2.282	.023	.068

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple ...

Table 47. Pairwise comparison of significant KW Living Arrangements for Question 17.

**Pairwise Comparisons of What are the living arrangements of the participant?**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
Own home (independently)-Own home (supported by family)	-2.566	14.429	-.178	.859	1.000
Own home (independently)-SBC	-70.963	28.341	-2.504	.012	.037
Own home (supported by family)-SBC	-68.397	29.977	-2.282	.023	.068

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple ...

## CENTRE-PD Top 10 Supplementary Material

Table 48. Pairwise comparison of significant KW Local Institute for Question 1.

**Pairwise Comparisons of Local Institute Country of Origin**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
UK-Germany	21.763	22.257	.978	.328	.985
UK-Luxembourg	119.038	18.740	6.352	.000	.000
Germany-Luxembourg	97.275	23.321	4.171	.000	.000

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 49. Pairwise comparison of significant KW Local Institute for Question 2.

**Pairwise Comparisons of Local Institute Country of Origin**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
UK-Germany	6.002	22.058	.272	.786	1.000
UK-Luxembourg	113.746	18.573	6.124	.000	.000
Germany-Luxembourg	107.744	23.112	4.662	.000	.000

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 50. Pairwise comparison of significant KW Local Institute for Question 4.

**Pairwise Comparisons of Local Institute Country of Origin**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
UK-Germany	94.481	22.247	4.247	.000	.000
UK-Luxembourg	108.551	18.731	5.795	.000	.000
Germany-Luxembourg	14.070	23.309	.604	.546	1.000

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 51. Pairwise comparison of significant KW Local Institute for Question 5.

**Pairwise Comparisons of Local Institute Country of Origin**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
Germany-UK	-51.890	22.617	-2.294	.022	.065
Germany-Luxembourg	125.238	23.698	5.285	.000	.000
UK-Luxembourg	73.348	19.043	3.852	.000	.000

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 52. Pairwise comparison of significant KW Local Institute for Question 6.

**Pairwise Comparisons of Local Institute Country of Origin**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
Germany-UK	-18.782	22.484	-.835	.404	1.000
Germany-Luxembourg	56.243	23.558	2.387	.017	.051
UK-Luxembourg	37.461	18.931	1.979	.048	.144

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

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Table 53. Pairwise comparison of significant KW Local Institute for Question 7.

**Pairwise Comparisons of Local Institute Country of Origin**

Sample 1–Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
UK–Germany	93.912	22.372	4.198	.000	.000
UK–Luxembourg	102.920	18.836	5.464	.000	.000
Germany–Luxembourg	9.008	23.440	.384	.701	1.000

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 54. Pairwise comparison of significant KW Local Institute for Question 8 .

**Pairwise Comparisons of Local Institute Country of Origin**

Sample 1–Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
UK–Germany	57.958	22.531	2.572	.010	.030
UK–Luxembourg	94.994	18.970	5.007	.000	.000
Germany–Luxembourg	37.036	23.607	1.569	.117	.350

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 55. Pairwise comparison of significant KW Local Institute for Question 9

**Pairwise Comparisons of Local Institute Country of Origin**

Sample 1–Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
UK–Germany	49.497	22.137	2.236	.025	.076
UK–Luxembourg	70.137	18.639	3.763	.000	.001
Germany–Luxembourg	20.640	23.194	.890	.374	1.000

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 56. Pairwise comparison of significant KW Local Institute for Question 10

**Pairwise Comparisons of Local Institute Country of Origin**

Sample 1–Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
UK–Germany	1.834	22.589	.081	.935	1.000
UK–Luxembourg	84.278	19.020	4.431	.000	.000
Germany–Luxembourg	82.445	23.668	3.483	.000	.001

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 57. Pairwise comparison of significant KW Local Institute for Question 11.

**Pairwise Comparisons of Local Institute Country of Origin**

Sample 1–Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
UK–Germany	11.778	22.534	.523	.601	1.000
UK–Luxembourg	83.648	18.973	4.409	.000	.000
Germany–Luxembourg	71.870	23.610	3.044	.002	.007

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

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Table 58. Pairwise comparison of significant KW Local Institute for Question 12.

**Pairwise Comparisons of Local Institute Country of Origin**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
UK-Germany	63.105	22.385	2.819	.005	.014
UK-Luxembourg	109.029	18.848	5.785	.000	.000
Germany-Luxembourg	45.924	23.454	1.958	.050	.151

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 59. Pairwise comparison of significant KW Local Institute for Question 13.

**Pairwise Comparisons of Local Institute Country of Origin**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
UK-Luxembourg	120.078	19.023	6.312	.000	.000
UK-Germany	153.041	22.594	6.774	.000	.000
Luxembourg-Germany	-32.963	23.673	-1.392	.164	.491

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 60. Pairwise comparison of significant KW Local Institute for Question 14.

**Pairwise Comparisons of Local Institute Country of Origin**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
UK-Germany	70.164	22.520	3.116	.002	.006
UK-Luxembourg	141.840	18.961	7.481	.000	.000
Germany-Luxembourg	71.676	23.595	3.038	.002	.007

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 61. Pairwise comparison of significant KW Local Institute for Question 15.

**Pairwise Comparisons of Local Institute Country of Origin**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
UK-Germany	9.039	22.549	.401	.689	1.000
UK-Luxembourg	144.470	18.986	7.609	.000	.000
Germany-Luxembourg	135.431	23.626	5.732	.000	.000

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 62. Pairwise comparison of significant KW Local Institute for Question 16.

**Pairwise Comparisons of Local Institute Country of Origin**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
Germany-UK	-56.909	22.577	-2.521	.012	.035
Germany-Luxembourg	78.865	23.655	3.334	.001	.003
UK-Luxembourg	21.956	19.009	1.155	.248	.744

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.



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Table 63. Pairwise comparison of significant KW Local Institute for Question 17.

**Pairwise Comparisons of Local Institute Country of Origin**

Sample 1–Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
Germany–UK	-35.418	22.636	-1.565	.118	.353
Germany–Luxembourg	107.128	23.717	4.517	.000	.000
UK–Luxembourg	71.710	19.059	3.762	.000	.001

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 64. Pairwise comparison of significant KW Local Institute for Question 18.

**Pairwise Comparisons of Local Institute Country of Origin**

Sample 1–Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
UK–Germany	14.288	22.577	.633	.527	1.000
UK–Luxembourg	89.761	19.010	4.722	.000	.000
Germany–Luxembourg	75.473	23.656	3.190	.001	.004

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 65. Pairwise comparison of significant KW Local Institute for Question 19.

**Pairwise Comparisons of Local Institute Country of Origin**

Sample 1–Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
UK–Luxembourg	54.551	18.688	2.919	.004	.011
UK–Germany	79.800	22.196	3.595	.000	.001
Luxembourg–Germany	-25.248	23.256	-1.086	.278	.833

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 66. Pairwise comparison of significant KW Local Institute for Question 20.

**Pairwise Comparisons of Local Institute Country of Origin**

Sample 1–Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
UK–Luxembourg	135.930	18.935	7.179	.000	.000
UK–Germany	140.596	22.488	6.252	.000	.000
Luxembourg–Germany	-4.666	23.562	-.198	.843	1.000

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 67. Pairwise comparison of significant KW Local Institute for Question 21.

**Pairwise Comparisons of Local Institute Country of Origin**

Sample 1–Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
UK–Germany	45.247	22.340	2.025	.043	.128
UK–Luxembourg	60.606	18.810	3.222	.001	.004
Germany–Luxembourg	15.360	23.407	.656	.512	1.000

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

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Table 68. Pairwise comparison of significant KW Local Institute for Question 22.

**Pairwise Comparisons of Local Institute Country of Origin**

Sample 1–Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
UK–Germany	53.300	22.708	2.347	.019	.057
UK–Luxembourg	154.569	19.120	8.084	.000	.000
Germany–Luxembourg	101.269	23.793	4.256	.000	.000

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 69. Pairwise comparison of significant KW Local Institute for Question 23.

**Pairwise Comparisons of Local Institute Country of Origin**

Sample 1–Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
UK–Germany	112.934	22.429	5.035	.000	.000
UK–Luxembourg	140.724	18.885	7.452	.000	.000
Germany–Luxembourg	27.790	23.501	1.183	.237	.711

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 70. Pairwise comparison of significant KW Local Institute for Question 24.

**Pairwise Comparisons of Local Institute Country of Origin**

Sample 1–Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
UK–Germany	78.873	22.591	3.491	.000	.001
UK–Luxembourg	130.968	19.021	6.885	.000	.000
Germany–Luxembourg	52.095	23.671	2.201	.028	.083

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 71. Pairwise comparison of significant KW Local Institute for Question 25.

**Pairwise Comparisons of Local Institute Country of Origin**

Sample 1–Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
UK–Germany	54.535	22.619	2.411	.016	.048
UK–Luxembourg	124.211	19.044	6.522	.000	.000
Germany–Luxembourg	69.677	23.699	2.940	.003	.010

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

Table 72. Pairwise comparison of significant KW Local Institute for Question 26.

**Pairwise Comparisons of Local Institute Country of Origin**

Sample 1–Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
UK–Germany	29.962	22.574	1.327	.184	.553
UK–Luxembourg	89.675	19.007	4.718	.000	.000
Germany–Luxembourg	59.713	23.652	2.525	.012	.035

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.

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Table 73. Pairwise comparison of significant KW Local Institute for Question 27.

**Pairwise Comparisons of Local Institute Country of Origin**

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.	Adj. Sig. <sup>a</sup>
UK-Germany	62.790	22.614	2.777	.005	.016
UK-Luxembourg	105.430	19.040	5.537	.000	.000
Germany-Luxembourg	42.640	23.694	1.800	.072	.216

Each row tests the null hypothesis that the Sample 1 and Sample 2 distributions are the same.

Asymptotic significances (2-sided tests) are displayed. The significance level is .050.

a. Significance values have been adjusted by the Bonferroni correction for multiple tests.