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1 **Prioritising target non-pharmacological interventions for research in Parkinson's**

2 **Disease: Achieving consensus from key stakeholders**

3 Angeliki Bogosian*¹, Lorna Rixon¹, Catherine S. Hurt¹

4 ¹Division of Health Services Research and Management, City, University of London, London, UK

5 *Address correspondence to Catherine Hurt, Division of Health Services Research and Management,
6 City, University of London, United Kingdom, Tel: +44(0)2070400883, email:
7 catherine.hurt.1@city.ac.uk

8
9 **Plain English summary**

10 In 2014 Parkinson's UK asked people with Parkinson's, their carers and healthcare professionals
11 working in Parkinson's, collectively known as stakeholders, to identify aspects of Parkinson's that
12 urgently needed to be researched to identify new treatments or management strategies. A range of
13 non-motor symptoms of Parkinson's were ranked as important including: sleep quality, stress and
14 anxiety, mild cognitive impairment, dementia and urinary problems. The purpose of this exercise was
15 to build on the work of Parkinson's UK by asking a group of stakeholders to identify and prioritise non-
16 drug treatments which should be researched as potential treatments for these non-motor symptoms.
17 This Patient and Public Involvement Exercise used some Delphi techniques to reach agreement on
18 which treatments should be prioritised. This consisted of a survey, followed by panel discussion and a
19 post panel survey. Nine people with Parkinson's and 10 healthcare professionals completed the first
20 round survey, 8 people with Parkinson's and 8 healthcare professionals participated in the panel
21 discussion and 13 people with Parkinson's completed the second round survey. There was good
22 agreement on research priorities between people with Parkinson's and Healthcare professionals.
23 Physical exercise, talking therapies and cognitive training were identified as treatments which had
24 shown some promising improvements in relevant symptoms, were acceptable to people with

25 Parkinson's and were practical to carry out and therefore should be the focus of research. There was
26 agreement that treatments which had the potential to improve multiple symptoms such as talking
27 therapies should be prioritised. The exercise provides a comprehensive list of practical and acceptable
28 non-drug treatments for non-motor symptoms of Parkinson's which can be used to push forward
29 research to improve the lives of people with Parkinson's and their families.

30 **Abstract**

31 **Background:** In 2014 Parkinson's UK conducted a research prioritisation exercise with stakeholders
32 highlighting important clinical research questions. The exercise highlighted the need for effective
33 interventions to be developed and tested to tackle a range of non-motor symptoms including: sleep
34 quality, stress and anxiety, mild cognitive impairment, dementia and urinary problems. The present
35 work set out to build on this exercise by prioritising types of non-pharmacological interventions to be
36 tested to treat the identified non-motor symptoms.

37 **Methods:** A Patient and Public Involvement Exercise was used to reach consensus on intervention
38 priorities for the treatment on non-motor symptoms. Some Delphi techniques were also used to
39 support the feedback collected. A first-round prioritisation survey was conducted followed by a panel
40 discussion. Nineteen panellists completed the first-round survey (9 people with Parkinson's and 10
41 professionals working in Parkinson's) and 16 participated in the panel discussion (8 people with
42 Parkinson's and 8 professionals working in Parkinson's). A second-round prioritization survey was
43 conducted after the panel discussion with 13 people with Parkinson's.

44 **Results:** Physical activity, third wave cognitive therapies and cognitive training were rated as priority
45 interventions for the treatment of a range of non-motor symptoms. There was broad agreement on
46 intervention priorities between health care professionals and people with Parkinson's. A consensus
47 was reached that research should focus on therapies which could be used to treat several different
48 non-motor symptoms. In the context of increasing digitisation, the need for human interaction as an
49 intervention component was highlighted.

50 **Conclusion:** Bringing together Parkinson’s professionals and people with Parkinson’s resulted in a final
51 treatment priority list which should be both feasible to carry out in routine clinical practice and
52 acceptable to both professionals and people with Parkinson’s. The workshop further specified
53 research priorities in Parkinson’s disease based on the current evidence base, stakeholder
54 preferences, and feasibility. Research should focus on developing and testing non-pharmacological
55 treatments which could be effective across a range of symptoms but specifically focusing on tailored
56 physical activity interventions, cognitive therapies and cognitive training.

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59 **Keywords:** Parkinson’s disease, research prioritisation, public and patient involvement, research
60 engagement, intervention development, self-management

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69 **Background**

70 In 2014 Parkinson's UK conducted a priority setting exercise to identify research questions that key
71 stakeholders, people with Parkinson's and clinicians, wanted to prioritise (1). The exercise highlighted
72 the need to identify and test effective treatments for a range of non-motor symptoms of Parkinson's
73 disease (PD) including stress and anxiety, dementia, mild thinking and memory problems, sleep and
74 urinary problems. The present work further developed this by asking stakeholders to prioritise
75 potential treatment types for the non-motor symptoms highlighted in the 2014 exercise.

76

77 PD is considered to be a movement disorder defined by the presence of motor symptoms, such as
78 bradykinesia, tremor and rigidity. It is now, however, widely accepted that PD is characterised not only
79 by its motor aspects, but also by numerous non-motor symptoms that encompass sensory
80 abnormalities, behavioural changes, sleep disturbances, autonomic dysfunction, and fatigue. In two
81 recent studies, at least one non-motor symptom was reported by almost 100% of patients (2). The
82 non-motor symptoms of PD can be as disabling for an individual as their motor symptoms, if not more
83 so (3). Indeed, non-motor symptoms dominate the clinical picture of PD and contribute to severe
84 disability, impaired quality of life, and shortened life expectancy (4, 5).

85

86 There is currently limited evidence for effective treatments for non-motor symptoms (6, 7), either
87 pharmacological or non-pharmacological. Consequently, even when non-motor symptoms are
88 recognised in a clinical consultation, treatment rates remain low as evidenced in recent reports (8, 9).

89

90 The failure to treat non-motor symptoms due to the lack of effective pharmacological treatments is
91 especially true in the case of fatigue, anxiety and depression in PD. People with PD benefit less from
92 antidepressant treatment, than do people without PD (10). Also, there is a high risk of adverse side

93 effects and adverse interactions between antidepressants and antiparkinsonian medications (11).
94 Benzodiazepines, used commonly for anxiety disorder treatment, are not recommended for people
95 living with PD due to adverse effects including cognitive and psychomotor impairment (12) and
96 increased risk of falls (13). Atomoxetine, was not found to be efficacious for anxiety in PD (14).
97 Currently insufficient evidence exists to support the treatment of fatigue in PD with any drug or non-
98 pharmacological treatment, highlighting the need for further research (15). Furthermore, there is
99 often a reluctance by many PD patients to take additional medication or change finely balanced
100 medication regimes for motor symptoms in order to treat non-motor symptoms (16).

101 For non-motor symptoms where pharmacological treatments lack effectiveness, there is a growing
102 evidence base showing that non-pharmacological treatments might be able to help. Cognitive
103 Behavioural Therapy (CBT), including distance delivered CBT, has moderate effects on improving
104 anxiety and depression, insomnia and impulse-control disorders in PD (17, 18). Emerging evidence has
105 suggested that mindfulness-based interventions can help reduce symptoms of depression (19-21), and
106 symptoms of anxiety (19, 21). Consequently the present exercise sought to prioritize non-
107 pharmacological treatments for a range of non-motor symptoms identified as priorities in the 2014
108 exercise, namely: stress and anxiety, dementia, mild thinking and memory problems, sleep and urinary
109 problems.

110

111 **Methods**

112

113 **Structure**

114 From the outset of this Patient and Public Involvement Exercise (PPIE) we decided to adopt elements
115 of the Delphi technique to guide the development of consensus. The purpose of the meeting was to
116 bring together relevant stakeholders to identify and prioritise psychological and behavioural
117 interventions which may improve non-motor symptoms. Using guidance from the Delphi technique
118 helped us to collect stakeholders' feedback in a more systematic way. The Delphi technique is an
119 iterative questionnaire exercise with controlled feedback to a group of panellists (22). The 'panellists'
120 are purposively selected for their particular expertise on a topic and the questionnaire exercise is often
121 conducted across a series of two or more sequential 'rounds'. In the current prioritisation exercise,
122 two rounds of questionnaires were used; one before and one following the panel discussion. The
123 structure of the process is outlined in figure 1. Patient and Public Involvement (PPI) was central to the
124 process as demonstrated in the Guidance for Reporting Involvement of Patients and the Public (GRIPP)
125 2- short form checklist (24) in table 1.

126 We brought together a range of key stakeholders: people with Parkinson's, psychological and
127 behavioural researchers specialising in Parkinson's, and healthcare professionals working in
128 Parkinson's. Bringing together all interested parties in a single day meeting allowed dialogue between
129 individuals and the sharing of perspectives to ensure that decisions regarding the final research
130 priorities were collaborative.

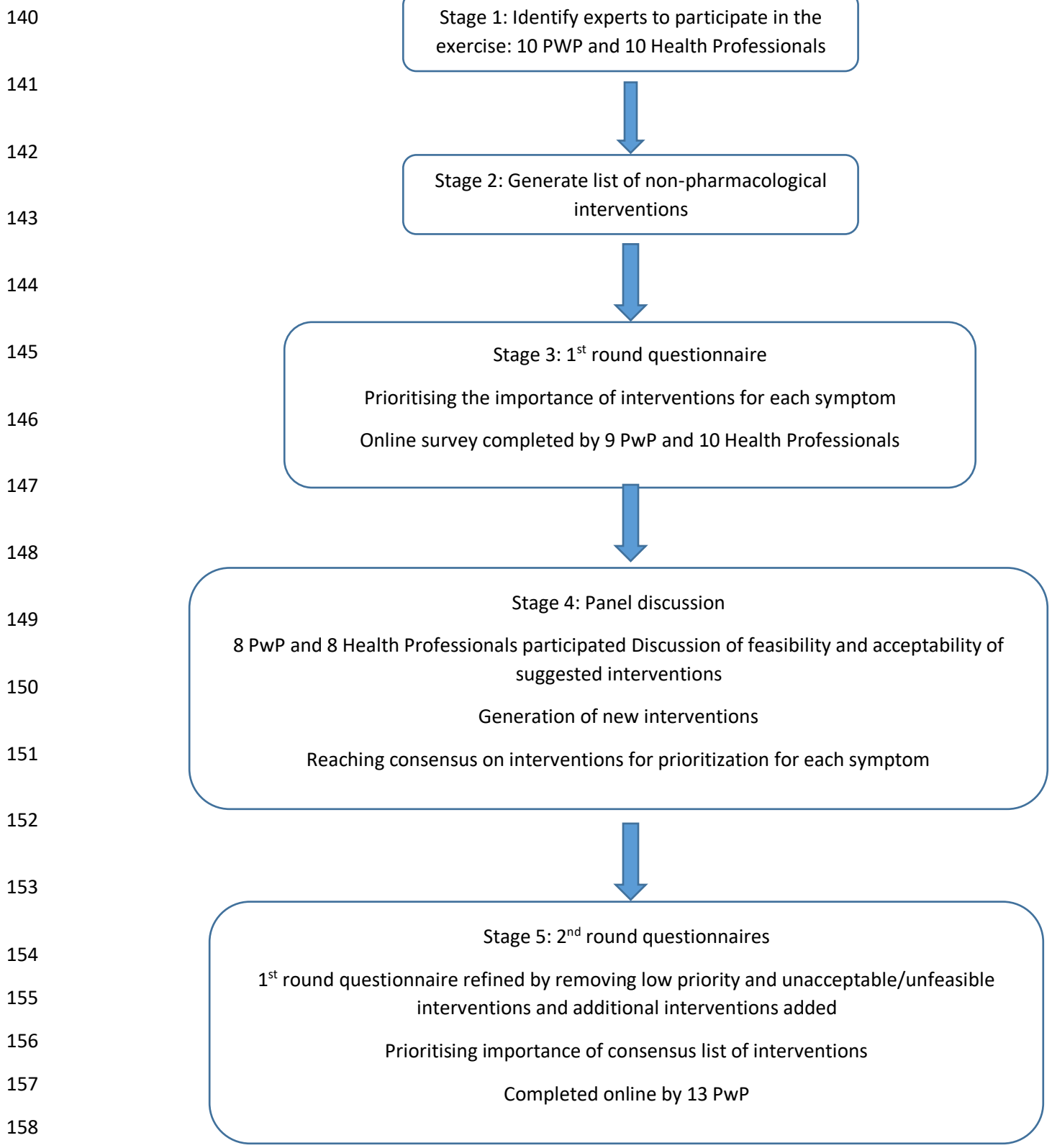
131

132 **Stage 1: Identifying experts for the exercise 'The panel'**

133 Turoff (25) recommends panels between 10 and 50. Ten people with Parkinson's and ten health
134 professionals (geriatrician, psychologists, PD nurses, physiotherapist, occupational therapist, speech

135 therapist) initially agreed to take part in the exercise. The health professionals, whose expertise was
136 based on qualifications and proven track records in the field, were identified through peer
137 consultation and invited via email by the authors. People with Parkinson's and carers were invited by
138 Parkinson's UK through an email to their Research Network mailing list.

139 **Figure 1. Delphi Flow chart**



159 PwP = People with Parkinson's

160

161

162 **Table 1 here**

163

164 **Stage 2: Generate list of non-pharmacological interventions**

165 The initial list of non-pharmacological interventions for the first round questionnaire was developed
166 from literature reviews in PD and similar conditions conducted by two authors (AB and LR) who
167 specialise in behavioural interventions in PD. Due to resource constraints the panellists were not
168 consulted in this initial idea generation phase for salient non-pharmacological interventions to include
169 in the survey.

170 **Stage 3: Survey round 1**

171 The survey rounds were completed using the online tool Survey Monkey (26). The survey asked
172 panellists to rank the importance of each suggested non-pharmacological intervention for each of the
173 non-motor symptoms identified as research priorities in the Parkinson’s UK prioritization exercise:
174 stress and anxiety, dementia, mild thinking and memory problems, sleep and urinary problems) (1). A
175 short explanation of each intervention was provided for clarity. Panellists were asked to rank the
176 interventions into order of treatment priority with 1 = highest treatment priority using a drop-down
177 menu. Respondents were then instructed to keep assigning numbers to each treatment until they
178 were sure that the treatment would not help for the symptom. Unhelpful treatments were not
179 assigned a number in the ranking. A screen shot of the treatment ranking exercise is shown in figure
180 2.

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186 **Figure 2. Treatment Priority Ranking in the Round One Survey**

Stress and anxiety

Please sort into order of treatment priority with 1 = to highest treatment priority. Keep going until you are sure that the treatment would not help for this problem. So unhelpful treatments will NOT be assigned a number in the ranking (sorting) 

⋮	1	Physical therapy (or physiotherapy, physical medicine and rehabilitation)
⋮	2	Parkinson's specific exercise classes
⋮	3	
⋮	4	Tai Chi, Yoga or Pilates
⋮	5	
⋮	6	
⋮	7	Shadow Boxing or boxing with pads (strength and co-ordination)
⋮	8	
⋮	9	
⋮	10	Dancing (strength and co-ordination)
⋮	11	
⋮	12	
⋮	13	Swimming (strength and mobility)
⋮	14	
⋮		Physical activity (personalised physical activity treatment)
⋮		Acceptance Commitment Therapy(accept what is out of personal control, and commit to actions that improve and enrich life)
⋮		Cognitive behavioural therapy (talking therapy that can help you manage your problems by changing the way you think and behave)
⋮		Mindfulness (process of bringing attention to the internal and external experiences occurring in the present moment)
⋮		Compassion Focused therapy (learning to practice self compassion)
⋮		Stress-Management (techniques aimed at controlling a person's levels of stress)
⋮		Technology Enabled care (Telehealth, telecare to facilitate monitoring of symptoms and health problems, identification of 'increased risk situations', remote monitoring of symptoms and events by healthcare professionals or care providers)
⋮		Caregiver support (teaching caregivers skills to identify problems and support people with Parkinson's)

[Comments and Other suggested treatments for Stress and anxiety](#) 

187

188

189 **Stage 4: The panel discussion in-between survey rounds**

190 The panel discussion was facilitated by the first and second author. All members of the panel were

191 made aware of the background of the two facilitators, i.e. health psychology researchers in the area

192 of non-pharmacological treatments in PD and were also made aware of their interest, i.e. identify

193 research priorities for future research grant applications. Respondents were aware of the topic of the

194 discussion and had already taken part in the survey that the discussion was based on. No other

195 preparation was required prior to the meeting. The panel discussion included eight people with
196 Parkinson's disease, and eight health professionals. The discussion started with a short presentation
197 on the most prevalent non-motor symptoms, followed by our suggestions for non-pharmacological
198 interventions, followed by the ranking results of the first-round survey. The non-motor symptom
199 priorities focused on during the workshop were: stress and anxiety, dementia, mild cognitive
200 problems, quality of sleep, urinary problems. For each of these categories, respondents were asked
201 to discuss:

202 -What behavioural and psychological management interventions are available?

203 -What is the research evidence and your personal experience with management of these non-motor
204 symptoms?

205 -Which behavioural and psychological management interventions do you consider as the highest
206 priorities?

207 The group discussed preferences in terms of types of psychological and behavioural interventions for
208 non-motor symptoms in Parkinson's, as well as the mode of delivery, that best suits people with
209 Parkinson's and how likely these interventions were to be translated into clinical practice. Current
210 clinical practices in Parkinson's were also discussed and how potential interventions on specific non-
211 motor symptoms could be added to current common practice.

212 The group then prioritised interventions for research based on potential intervention efficacy,
213 acceptability, need and translation into clinical practice. After discussing specific treatments, the
214 facilitators asked the group which non-pharmacological intervention they consider the most
215 important and promising. One of the panelists kept notes on a white board as people offered
216 suggestions and thoughts. This discussion largely focused on one specific intervention and the
217 facilitators summarised and confirmed with the group that this intervention should be prioritised.

218

219

220

221 **Stage 5: Survey round 2**

222 Following the panel discussion, the first-round survey was refined by adding interventions not
223 previously included and narrowing down the available intervention options for each non-motor
224 symptom. We removed interventions with very low rankings at the first survey or interventions that
225 were not considered appropriate based on the panel discussion. For example, we added 'peer group
226 support' under 'anxiety' and removed 'acceptance and commitment therapy' under 'sleep'. A
227 question about mode of delivery preferences was also added.

228 For the second-round survey we asked the panel to re-rate the interventions suggested for each non-
229 motor symptom and emailed the survey to Parkinson's UK Research Network members. Thirteen
230 people with Parkinson's responded to the survey, two of whom had attended the workshop.

231

232 **Ethics**

233 The goal of the project was to gather information to direct future research using Public and Patient
234 Involvement. According to NIHR INVOLVE guidelines ethical approval is not needed when the public
235 acts as specialist advisors, providing expertise based on their experience of a health condition in
236 planning or advising on research. Prior published research priority setting exercises have also
237 suggested that ethical approval is not required (1). It was assumed that the ability to complete the
238 online surveys suggested that the respondents had capacity to consent in the exercise. No
239 incentives were offered to respondents but all travel expenses were reimbursed.

240

241

242 **Results**

243 *Intervention Ranking*

244 The results of the first-round survey showed that physical activity, stress-management and cognitive
245 training were high priorities for a variety of non-motor symptoms. More details on the top three
246 behavioural interventions for each non-motor symptom are presented in table 2. Physical activity,
247 cognitive training and third wave therapies including cognitive behaviour therapy and mindfulness
248 were all ranked as high priorities in the second-round survey.

249

250 **Table 2 here**

251

252 During the panel discussion additional behavioural interventions were discussed, such as peer support
253 groups to manage stress and anxiety; on-going assessments and care for dementia, pelvic floor
254 exercises as part of self-management for urinary problems and massage and the use of a light box to
255 help manage sleep. These non-pharmacological interventions were added in the post-panel survey,
256 but they were not identified as a priority (table 2). Table 3 summarizes the number of interventions
257 that were added and removed at each stage of the process.

258

259 **Table 3. Number of non-pharmacological interventions in advance of, during and after the panel**
 260 **discussion**

Key non-motor symptoms	Total number of interventions generated at pre-discussion survey	Number of interventions remaining following discussion	of Additional interventions generated during panel discussion	Final number of interventions for ranking
<i>Stress and anxiety</i>	14	7	1	8
<i>Dementia</i>	17	5	1	6
<i>Mild thinking and memory problems</i>	17	7	0	7
<i>Quality of sleep</i>	17	5	2	7
<i>Urinary problems</i>	4	0	0	4

261

262

263 As shown in table 2, the three highest ranked interventions for each non-motor symptom did not
 264 change significantly between the first and second survey rounds. Ten HCPs and 10 people with
 265 Parkinson’s responded to the first-round survey and 13 people with Parkinson’s responded to the
 266 second-round survey. Table 4 shows the first-round survey responses divided by respondent type
 267 (professional vs person with Parkinson’s). There was broad agreement on intervention priorities
 268 across respondent group.

269

270 **Table 4. First round survey priorities by respondent type**

Key non-motor symptoms	Professionals top three interventions	People with Parkinson’s top three interventions
<i>Stress and anxiety</i>	<ol style="list-style-type: none"> 1. Cognitive behavior therapy 2. Mindfulness 3. Stress management 	<ol style="list-style-type: none"> 1. Cognitive behavior therapy 2. Stress management 3. Mindfulness
<i>Dementia</i>	<ol style="list-style-type: none"> 1. Cognitive skills training 2. Lifestyle management strategies 3. Carer support 	<ol style="list-style-type: none"> 1. Cognitive skills training 2. Carer support 3. Compassion focused therapy
<i>Mild thinking and memory problems</i>	<ol style="list-style-type: none"> 1. Cognitive skills training 2. Acceptance and commitment therapy 3. Stress management 	<ol style="list-style-type: none"> 1. Cognitive skills training 2. Cognitive behavior therapy 3. Physical activity
<i>Quality of sleep</i>	<ol style="list-style-type: none"> 1. Sleep hygiene 2. Cognitive behavior therapy 3. Self-management 	<ol style="list-style-type: none"> 1. Physical activity 2. Sleep hygiene 3. Mindfulness
<i>Urinary problems</i>	<ol style="list-style-type: none"> 1. Self-management 2. Lifestyle management 3. Carer support 	<ol style="list-style-type: none"> 1. Self-management 2. Lifestyle management 3. Carer support

271

272

273

274 *Mode of delivery*

275 In the second-round survey a question was added exploring preferences for mode of delivery of non-
276 pharmacological interventions. Of the 13 PD respondents, eight preferred individual face-to-face
277 delivery of interventions, four preferred online delivery with some peer or professional contact, and
278 one wanted group support or group therapy.

279

280 *Outcomes from the panel discussion*

281 There was consensus that physical exercise is beneficial in PD but there is limited knowledge on PD
282 specific exercises. There was also a consensus that ideally, we need an intervention that will cover
283 more than one symptom. For example, talking therapies could be applied to more than one non-
284 motor symptom at a time, such as anxiety, depression, and sleep problems, and augment other
285 treatment approaches, such as facilitating adherence to exercise, pacing activities of daily living and
286 self-management.

287 People with Parkinson's emphasised the need for personalised treatments. They were aware that one
288 size did not fit all and that the same symptoms can impact people differently, so they needed to be
289 cautious when suggesting one treatment for one symptom in all cases. In order to get the maximum
290 potential benefit from treatments delegates agreed that treatments need to be tailored to the
291 individual.

292 With the increasing use of digital technologies to deliver interventions the panel reached a consensus
293 that face to face contact in intervention delivery remained of central importance as a method of
294 combating social isolation.

295

296

297 **Discussion**

298 This exercise extended the priority setting work conducted by Parkinson's UK (4) with a focus on
299 prioritising non-pharmacological treatments to tackle the non-motor symptoms highlighted by the
300 Parkinson's UK exercise namely: sleep quality, dementia, mild memory problems, stress and anxiety
301 and urinary problems.

302 There was good consensus on treatment priorities between Parkinson's professionals and people with
303 Parkinson's. Many overlapping interventions were identified for different symptoms for example
304 physical activity, cognitive skills training and mindfulness. While both people with PD and healthcare
305 professionals generally ranked physical activity as a priority it was evident that there was a lack of
306 clarity around which physical exercises were recommended for people with Parkinson's. Research to
307 date has shown physical exercise to have beneficial effects on a range of non-motor symptoms (27).
308 Future research should focus on providing evidence-based guidance for physical activity in PD that can
309 be easily implemented by clinicians and patients.

310 Similarly, there is accumulating evidence for the efficacy of cognitive skills training in PD (28) but there
311 is large methodological variability between studies and a limited understanding of the long-term
312 efficacy of this approach. Future research should seek to conduct larger, controlled studies which aim
313 to determine which patient groups may benefit most from cognitive skills training (28) enabling
314 targeted provision for those who will benefit most.

315 The efficacy of third wave therapies such as mindfulness, cognitive behaviour therapy and stress
316 management is increasingly being tested for a range of non-motor symptoms in PD (19-21, 29-31) with
317 some positive preliminary results. Large, controlled trials with longer follow up periods are needed.

318 A challenge of providing these interventions is often one of resource, particularly when a trained
319 therapist is required to implement an intervention. Despite the recent proliferation of online
320 interventions in Parkinson's (29, 30, 32) which have clear practical benefits, there was a consensus

321 that an element of face-to-face contact was required in intervention delivery. It is essential to carefully
322 balance the preferences of people with Parkinson's with the practicalities of delivering cost-effective
323 interventions to large groups. Consequently, finding innovative ways to implement the intervention
324 whilst still maintaining human contact, rather than taking a purely digital approach, is paramount.
325 Recent work exploring the use of skype conferencing to deliver mindfulness interventions (29, 33) or
326 the use of lay facilitators to deliver interventions across conditions may be important avenues for
327 further research (34-36).

328 It was evident from the panel discussion that rather than treatments tailored to symptoms, people
329 with Parkinson's and professionals working in the area of Parkinson's wanted global interventions
330 which might have positive effects across a range of symptoms. Future research should endeavour to
331 explore the use of therapies such as CBT and mindfulness to support self-management of other non-
332 motor symptoms e.g. urinary symptoms and cognitive symptoms.

333 Bringing together Parkinson's professionals and people with Parkinson's allowed both parties view's
334 to be heard, combining feasibility of delivering an intervention with patient and carer preferences.
335 Asking stakeholders to produce a consensus list of priority interventions helps ensure that the
336 research agenda moves forward and research into identified interventions is undertaken as
337 stakeholders are engaged with the research process. The final treatment priority list should be both
338 feasible to carry out in routine clinical practice and acceptable to both professionals and people with
339 Parkinson's increasing the likelihood of implementation of effective interventions in the NHS.
340 Furthermore, the bringing together of clinicians, researchers and people with PD provides strategic
341 alliances facilitating future research programmes.

342 This priority setting exercise was not without limitations. The largest of these being the difference in
343 respondents completing the survey pre and post the panel discussion. The first-round survey was 50%
344 people with Parkinson's and 50% professionals, the majority of whom then attended the panel
345 discussion. However, the second-round survey was solely completed by people with Parkinson's, only

346 a small proportion of whom attended the discussion. Possible reasons for the lack of engagement in
347 the second-round survey could include the realities of a busy schedule or panellists may have felt that
348 they had 'already had their voice heard'. This latter point may have been more salient in the present
349 exercise as relatively few changes were made to the intervention list as a consequence of the panel
350 discussion. Therefore respondents may have felt the process had an element of repetition.

351 It is possible that the interventions prioritized in the second-round survey only reflect the views of
352 people with Parkinson's as no professionals completed this round. However, the concordance in
353 priority setting seen between professionals and people with Parkinson's in the first-round survey
354 suggests that the second-round survey results may have been relatively similar had it also been
355 completed by Parkinson's professionals. Conversely the inclusion of a largely new group of
356 respondents in the second-round survey provides support for the generalisability of the findings in the
357 first round of the survey. Treatment priorities showed little variation pre and post panel discussion.

358 **Conclusions**

359 In summary, the present exercise further specifies research priorities in Parkinson's disease based on
360 the current evidence base, stakeholder preferences, and feasibility. Research should focus on
361 developing and testing non-pharmacological treatments which could be effective across a range of
362 non-motor symptoms but specifically focusing on tailored physical activity interventions, cognitive
363 skills training and psychological therapies including mindfulness, cognitive behavioural therapy and
364 stress management.

365

366

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368

369 **List of abbreviations**

370 CBT - Cognitive behavioural therapy

371 HCP- Health Care Professional

372 PD – Parkinson’s disease

373 PPI – Patient and public involvement

374 PwP – Person with Parkinson’s

375

376

377 **Declarations**

378 • Ethics approval and consent to participate

379 Not applicable

380 • Consent for publication

381 Not applicable

382 • Availability of data and material

383 The datasets used and analysed during the current study are available from the corresponding author
384 on reasonable request.

385 • Competing interests

386 The authors declare that they have no competing interests

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390 interpretation of data, nor in writing the manuscript.

391 • Authors' contributions

392 AB designed the study, conducted the surveys and workshop and helped draft the paper

393 CH designed the study and drafted the paper

394 LR conducted the surveys and workshop and contributed to the writing of the paper

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398

399

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489 **Table 1 PPI in the non-pharmacological treatment prioritisation exercise using GRIPP2-SF**

Section and Topic	Item
<p>1. Aim</p> <p>Report the aim of the study</p>	<p>To collaboratively involve patients in the prioritization of non-pharmacological treatment types for the management of non-motor symptoms.</p>
<p>2. Methods</p> <p>Provide a clear description of the methods used for PPI in the study</p>	<p>10 patient partners were recruited as panelists for the prioritization exercise. They were involved in discussions refining the intervention prioritization list, took part in the consensus workshop and the intervention prioritization exercise. A further 11 patient partners were involved in the 2nd round intervention prioritization exercise.</p>
<p>3. Results</p> <p>Outcomes – report the results of PPI in the study, including both positive and negative outcomes</p>	<p>PPI contributed to the study in several ways including:</p> <p>Providing patient experience and perspectives to inform discussions to refine the intervention prioritization list. Prioritized non-pharmacological intervention types for a range of non-motor symptoms in the first and second round surveys to provide a definitive list of research priorities.</p>

4. Discussion

Outcomes – comment on the extent to which PPI influenced the study overall.

Patient involvement in this process was highly influential. Using the experience and understanding the preferences of patients was central to the prioritization exercise which was intended to be a collaboration between stakeholders. The final list of research priorities was strongly influenced by patient involvement.

5. Reflections

PPI was embedded into the exercise from the outset and PPI panelists were able to meaningfully engage in the prioritization exercise. The small number of patients from round 1 and the panel discussion retained at round 2 is a limitation. In future exercises safeguards will be put in place in an attempt to minimize attrition such as scheduling survey completion times and following up non-responders.

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Table 2. Top three non-pharmacological interventions identified for each non-motor symptom in the first and second round surveys

Non-motor symptom	Interventions (1 st round survey)	Panel discussion (consensus discussion of efficacy, acceptability and need)	Interventions (2 nd round survey)
Stress and anxiety	<ol style="list-style-type: none"> 1. Cognitive behavioural therapy (talking therapy that can help you manage your problems by changing the way you think and behave) 2. Stress management (techniques aimed at controlling a person's levels of stress) 3. Mindfulness 	<ol style="list-style-type: none"> 1. Acceptance and commitment therapy (acceptance and committing to valued actions) 2. Mindfulness 3. Cognitive behavioural therapy (talking therapy that can help you manage your problems by changing the way you think and behave) 	<ol style="list-style-type: none"> 1. Physical activity (personalised physical activity) 2. Cognitive behavioural therapy (talking therapy that can help you manage your problems by changing the way you think and behave) 3. Mindfulness
Dementia	<ol style="list-style-type: none"> 1. Cognitive skills training (compensatory 	<ol style="list-style-type: none"> 1. Screening programme to 	<ol style="list-style-type: none"> 4. Lifestyle management strategies

	(techniques aimed at controlling a person's levels of stress)	neurorehabilitation)	neurorehabilitation)
	3. Physical activity (personalised physical activity treatment)	Caregiver support (teaching caregivers skills to identify problems and support people with Parkinson's)	3. Stress management (techniques aimed at controlling a person's levels of stress)
Quality of sleep	1. Sleep hygiene 2. Physical activity (personalised physical activity treatment) 3. Mindfulness	1. Sleep hygiene 2. Technology Enabled care (to monitor sleep, but also falls and nocturia at night)	1. Sleep hygiene 2. Physical activity (personalized physical activity treatment) 3. Mindfulness
Urinary problems	1. Self-management for urinary problems (fluid management, caffeine and alcohol management, bladder retraining)	1. Self-management for urinary problems (fluid management, caffeine and alcohol management, bladder retraining)	1. Self-management for urinary problems (fluid management, caffeine and alcohol management, bladder retraining)

2. Lifestyle

management

strategies

3. Technology

Enabled care

2. Lifestyle

management

strategies

3. Technology

Enabled care

§ = includes physiotherapy and rehabilitation §§ = exercise classes and program