Priority Setting Partnership to Identify the Top 10 Research Priorities for the Management of Parkinson's Disease

For which topic were research priorities identified?
Parkinson's disease

In which location was the research priority setting conducted?
Europe - United Kingdom

Why was it conducted at all?
Ensuring that research is effective in addressing the needs of patients and the clinicians treating them is critically important. The research agenda has been accused of being overly influenced by the pharmaceutical and medical devices industries, and of not addressing the questions about treatments that are of greatest importance to patients, their carers and clinicians. Research needs to focus on whether treatments are doing more harm than good, or whether one treatment is better than another, and ensure the outcomes reflect issues that have impact on the patient's well-being and participation.

What was the objective?
to encourage people with direct and personal experience of Parkinson's disease to work together to identify and prioritize the top 10 evidential uncertainties that impact on everyday clinical practice for the management of Parkinson's disease

What was the outcome?
a ranking list of 10 research questions

How long did the research prioritization take?
No information provided.

Which methods were used to identify research priorities?
JLA method

How were the priorities for research identified exactly?
Step 1: setting up PSP: identifying partner organizations. Step 2: consultation via survey: survey that asked about four areas where participants would like to see issues answered by research, 4100 responses. Step 3: data processing: data collation, 2632 research uncertainties identified from responses of which 112 were unique, submissions transformed into PICO format, duplicates combined, frequency of duplicated uncertainties recorded, resulting PICO questions checked against evidence base. Step 4: interim ranking: 18 submissions were excluded from interim ranking by the steering group as they had less than three duplicate submissions and were deemed to be unlikely to be important enough to reach the top 10 priorities, survey with 94 uncertainties: participants were asked to identify their own top 10 priorities, votes for each uncertainty statement were scored in reverse, then summated and divided by the number of participants from each group of participants (PwP, carers, family and friends, and professionals) and ranked in order of priority, these four sets of ratings were then added together and again ranked to identify the top 26 for all participants. Step 5: final prioritization: workshop: prior to the meeting participants were asked to prioritize the top 26 uncertainties, during workshop participants divided into three groups with mixed representation and asked to prioritize all 26 uncertainties, participants divided into three different groups and again asked for ranking, group rankings then combined, plenary consensus on top 10

Which stakeholders took part?
People with Parkinson's (PwP), carers and former carers, family members and friends, healthcare and social care professionals who work, or have worked, with people living with the condition. Survey: 1000 participants of which 600 persons with PD, 135 carers, 86 family and friends, 140 healthcare professionals: consultants (24%), PD nurse specialists (19%), nurses and care assistants (9%), allied health professionals (31%), social workers (1%) and others (16%). Interim ranking: 475 participants consisting of 342 PwP, 57 carers, 34 friends and family. Workshop: 27 participants including 10 PwP, 5 carers and family, 5 consultants, 4 PD nurse specialists and 3 allied health professionals.

How were stakeholders recruited?
Participants were invited to complete the survey on the Parkinson's UK website or by post. Parkinson's UK advertised the study in their membership magazine, on their website and targeted relevant groups at meetings and conferences including Parkinson's UK also advertised the project directly to centres of clinical excellence throughout the country. Relevant charities were contacted to promote participation to their members via flyers, magazine articles and social media. The project team contacted professional groups with an interest in PD. Parkinson's UK's database of people from black and minority ethnic populations who have an interest in PD was also used. The final set of uncertainties were then sent to participants who had provided their contact details and to the members of the Research Support Network. It was also advertised in an article in the Parkinson's UK membership magazine and promoted through