Patient and public involvement advisory group for Parkinson's clinical trials programme

Description: Patient advisory group working with biotech company to provide input on planned clinical trials (phases I-III) for Parkinson's vaccine
PEQG: Used Quality Criteria to review the work of past 6 months and plan for future

1. Discussing PE Quality clarified the purpose and aim for the group. Shared purpose: To maximise the potential of the UNS research programme, improve recruitment to the clinical trials and improve the overall experience for participants in the study.
2. Open and honest dialogue, with all members of the group as equal partners in discussions. As a result of using the PE Quality Criteria we developed terms of reference for the group.
3. Advisory group will work together to identify where and when it will be necessary to involve a wider group of people affected by Parkinson's to provide input.
4. PPI advisors signed agreements at the start of the project, outlining general expectations for all, acknowledging that their role evolves over time.
5. Using the PE Quality Criteria has helped build capabilities for the United Neuroscience team.
6. Feedback during completion of PE Quality Criteria highlighted need to review process for sharing meeting notes and actions
7. Aim is to embed patient engagement as part of the process for the Parkinson's vaccine trials and apply learnings to other branches of company's R&D programme. Plan to create a 'Lessons Learned' debrief at the end of the project.

Impact: 1) Strengthened relationship between Parkinson's UK and United Neuroscience, 2) Helped clarify the purpose and the aims for the advisory group, 3) Provided a tool to evaluate our progress so far, 4) Unexpected outcome - pause on the advisory group until 2020 (to ensure meaningful patient engagement activities that can make the most impact on the research)
Lessons learned: 1) PE Quality Guidance provided a common framework for the group, 2) Highlighted importance of regular feedback review points and keeping clear documentation throughout the project, 3) Need to allocate time to complete PE Quality Guidance in order to maximise its usefulness, 4) Changes to research plans will require review, and potentially revision, of patient engagement plans.

PATIENT FOCUSED MEDICINES DEVELOPMENT

Patient Engagement open forum Beyond Aspiration