Engaging People with Parkinson’s in Clinical Research Working Group Members
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Working Group Vision
The Engaging People with Parkinson’s in Clinical Research Working Group was established to support the availability of inclusive research and the involvement of people living with Parkinson’s (PwPs) in shaping the research. Working with key stakeholders, the Working Group aims to develop global standards to support clinical research and to encourage adoption of these standards.

Activities to Date
- Identified Working Group objectives
- Surveyed industry stakeholders for their viewpoint on barriers and challenges
- Surveyed the barriers experienced by PwPs in participating and engaging in research
- Created European Parkinson’s Disease Association Research (EPDA) interest group to further explore relevant topics revealed by industry and PwP surveys
- Began collating resources to develop a relevant resource toolkit

Surveying the Industry Sector
The Working Group conducted a survey of 91 individuals representing 50 organizations from the pharmaceutical, biotech, and health tech industries. Respondents represented a diverse set of roles within the for-profit sector, from senior management to patient engagement/advocacy roles. The survey focused on how to engage PwPs in research, with a specific intention of identifying opportunities and challenges in increasing PwP participation. It also sought perspective on whether new approaches to clinical research are being considered in a post-Covid world.

Key takeaways from this survey:
- The **top three areas** where PwPs provide added value to a clinical research process:
  - Identifying unmet needs
  - Educating the industry team about Parkinson’s
  - Preparing/reviewing a study’s protocol and helping to develop and/or review a study concept
While most respondents agreed or were neutral about the value of engaging PwPs in study prioritization, design and implementation, most felt the process of engagement was time consuming. Reasons listed include:
- Lack of understanding about how to engage PwPs
- Uncertainty about compliance guidelines

Many of the recruitment barriers identified by industry stakeholders mirrored results of the Working Group’s survey of PwP, including:
- Access to research
- Awareness and communication of research
- Addressing fears of side effects and medication changes

More than half of respondents confirmed that their company is considering new approaches to conducting research in a post-Covid world.

Surveying PwPs — EPDA Survey Results
The EPDA is an umbrella organization made up of 20 European member organizations. It supported the Working Group by collecting information from respondents in 18 countries through its members. It found that research opportunities are generally promoted via individual research centres promoting only their own research, as opposed to Parkinson’s organizations and aggregator tools such as Fox Trail Finder.

The most common type of research conducted: symptomatic therapeutic trials
Least common: genetic trials

Key barriers to PwPs participating in clinical trials:
- Accessibility and travel/transportation
- Lack of information offered to participants
- Fear of side effects and changes to medication routine
- Lack of consultation and support from health care professionals
- Inconvenient timing
- Poor communication — before, during, and after the trial
- Lack of collaboration between research centres, institutions and patient organizations
- One-third of respondents did not have tools or resources in their own language

More survey results are available by request.

EPDA Research Group
This Research Group was formed to further explore the results revealed by the Working Group’s surveys of industry stakeholders and PwPs. Its members currently represent 11 countries. It aims to further identify and address barriers and solutions to engaging with research, as well as explore other opportunities to support Parkinson’s research. It will help raise awareness and improve access to clinical trials for PwPs.

The Research Group’s working themes:
- Aggregation of information
- Education and training
- Data collection
o Identifying what is meaningful to collect and how — clinical trial and real-world information
o Determining how consent works
o Establishing trust through security and a strong code of conduct
o Ensuring patients are in control of what information is available to researchers

Critical Collaborations
The Working Group will be collaborating with the Equity, Access and Inclusion Working Group to map the basic principles of involvement in trials, and from this pilot a health equity advisory/checklist to help create the standard for more equitable and inclusive clinical research — i.e., research that includes a diverse group of participants including different stages of Parkinson’s, ethnicities and races, genders, rural vs. urban, income levels, and LGBTQ+. This collaboration will:

● Co-create a Clinical Trials Equity Statement
● Identify the qualities and skills of trusted Parkinson’s community leaders to act as a bridge to clinical research and build valuable partnerships
● Participate in each other’s meetings and committee work

The Working Group also will be collaborating with the Technology Working Group to evaluate digital aids that may support PwPs engaging in clinical research. This collaboration will:

● Broker introductions to Critical Path for Parkinson’s, the MDS Technology Task Force, and other organizations
● Share knowledge of digital outcomes currently being developed/evaluated in clinical trials and feed it into an Inventory and assessment of digital aids
● Gain a better understanding of the technology being implemented in trial delivery as a result of Covid-19

Global Standards for Clinical Research
During breakout groups, Leadership Forum participants discussed the process of creating shared standards for global clinical research and raised some critical points, including:

● It is important to simplify and improve the quality of communication from those running clinical trials to PwPs.
● It is important for clinical trials to make a case to PwPs about why they should participate.
● Regarding the creation of equity standards, it is key to discuss what diversity means, how it is reflected in supporting materials, and for organizations to consider it in every aspect of clinical research programs.
● It is critical that organizations share their results.
Next Steps
The Working Group will be working on the following projects over the next several months:

- Taking steps to ensure the accessibility of information about clinical research opportunities — e.g., translation
- Creating a resource tool kit
- Continuing to look at global standards for clinical research
- Planning for the 6th World Parkinson Congress in July 2023 in Barcelona and how best to maximize this opportunity

What’s Next
The Working Group is seeking help. Audience members are encouraged to contact the Working Group if they’d like to add to the conversation around clinical research or join the general Working Group.

Questions for the Clinical Research Working Group?
Contact. Helen Mathews at helen@cureparkinsons.org.uk

Questions for the WPC?
Contact Elizabeth Pollard at eli@worldpdcoalition.org

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