World Parkinson Coalition Leadership Forum 2021
Presentation summary from June 2021

Technology Working Group Members
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Working Group Goal
The Technology Working Group was created to explore existing technology that can improve the lives of People with Parkinson’s (PwPs) and promote innovative actions. Despite the numerous benefits that technology can offer PwPs, there is no centralized location that catalogs existing technologies, devices, and services and there is no consensus on which are most effective.

As a result:

- PwPs do not know about many technology options or have the ability to access them.
- Technology efforts often are duplicated.
- Opportunities for collaboration are missed.

Working Group Activities
The Working Group wants to reach out to PwPs and Parkinson’s organizations to gather more insight. It will be conducting surveys and working with WPC partner organizations to learn more about the technology needs, desires, uses, and gaps. It will create an internal working database, or catalog, containing what technologies exist for PwPs. As part of this, the Working Group will be identifying experts and creating a task force with the purpose of assessing existing technologies, identifying gaps and opportunities, and offering recommendations to the tech community.

Breakout Groups
The Working Group conducted breakout sessions to help with the development of its planned activities. Groups discussed what information would be helpful to collect from WPC partner organizations, what partners or other organizations may be valuable to the discussion, how the Working Group best reaches them, what databases may already exist, and what obstacles to these activities may present themselves.
Some key takeaways shared with the general group:

- When collecting and evaluating information, it’s helpful not to make assumptions about who does or doesn’t have access to technology.
- It’s important to **consider data security and privacy** when choosing what tech companies to include — i.e., understand motivations and evaluate intentions, ensure strong privacy policies are in place.
- **Surveys should include organizations, but also PwPs and those supporting them who use the technology** — simple, user-friendly language.
- Technology can be overwhelming, and a catalog or database would be valuable.
- Significant consideration should be given to how the technology database is categorized and made searchable by users.
- It’s valuable to **consider including in the database technology that is not specific to Parkinson’s** but applicable to PwP needs.
- Working Group recommendations may include Parkinson’s-specific **tweaks** that can be made to non-Parkinson’s-specific technology.
- COVID-19 opened up the Parkinson’s community’s eyes to the value of technology in their world.
- **Collaboration opportunities may exist** with groups doing similar work, including universities and other organizations with technology-focused working groups.
- **Telemedicine is a significant part of this ongoing conversation**, including as it relates to access gaps and reaching a broader swath of the medical community with this technology.

Questions for the Technology Working Group?
Contact Fulvio Capitanio at Fulvio.capitanio@gmail.com

Questions for the WPC?
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