

Empowering Patients through AI: Enhancing Communication and Engagement in Neuroscience



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Disclosures

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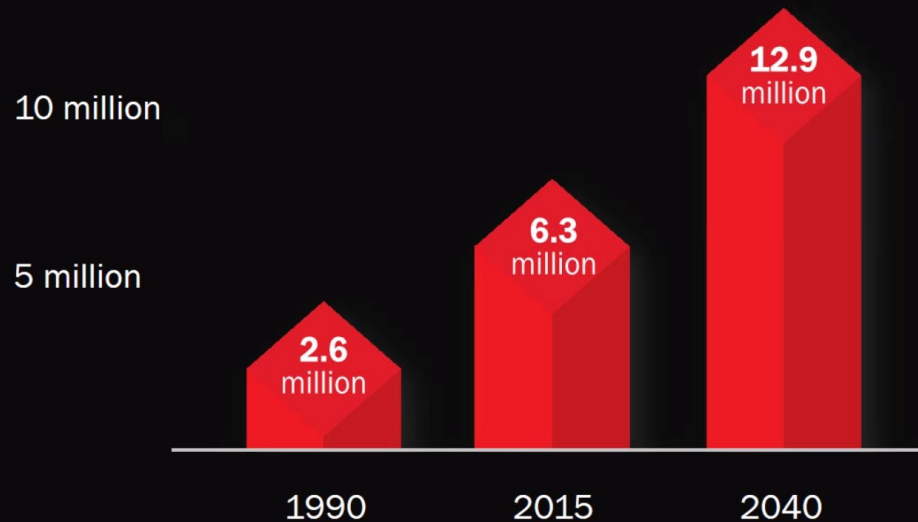
Summary of the talk

- Research focus on AI for diagnosis; less on communication & engagement
- Challenges in AI research partnerships formation
- Difficulty publishing these findings in AI conferences



Parkinson's disease

...but is now the fastest growing brain disease ...



Source: Dorsey ER, Bloom BR. The Parkinson Pandemic—A Call to Action. *JAMA Neurol*. 2018;75(1):9-10. doi:10.1001/jamaneurol.2017.3299

In 23 African countries, average population per neurologists exceeds 6M

40% of PD patients over 65 do not receive care from a neurologist in the US



Economic Burden due to PD

The total economic burden in USA (2017)
=**\$52B**

Projected to be **\$80B** by 2037.

Yang, W., Hamilton, J.L., Kopil, C. et al. Current and projected future economic burden of Parkinson's disease in the U.S.. *npj Parkinsons Disease*. 6, 15 (2020).





<https://www.youtube.com/watch?v=cxHpFWKIfGw>

Parkinson's Analysis w/ Remote-Kinetic Tasks (PARK)



parktest.net



M.S. Islam, W. Rahman, A. Abdelkader, S. Lee, P.T. Yang, J.L. Purks, J.L. Adams, R.B. Schneider, E.R. Dorsey, and E. Hoque, [Using AI to Measure Parkinson's Disease Severity at Home](#), *Nature Digital Medicine* 2023.

W. Rahman, M. Hasan, M. S. Islam, T. Olubajo, J. Thaker, A. Abdelkader, P. Yang, H. Paulson, G. Oz, A. Durr, T. Klockgether, T. Ashizawa, E. Hoque, [Auto-Gait: Automatic Ataxia Risk Assessment with Computer Vision from Gait Task Videos](#), *Proceedings of ACM on Interactive, Mobile, Warble, and Ubiquitous Computing (IMWUT)*, 2023



START

Tasks



Task 1
**Right
Finger
Tapping**



Task 2
Smile



Task 3
**Quick
Brown Fox**



Start Task

Mock Results

Your overall score suggests that you are
VERY UNLIKELY
to be demonstrating features of Parkinson's disease



Speech Tasks Result

SEVERITY : Normal



Facial Tasks Result

SEVERITY : Normal



Motor Tasks Result

SEVERITY : Normal

A. Results shown to control

Mock Results

Your overall score suggests that you are
LIKELY
to be demonstrating features of Parkinson's disease



B. Results shown to PwP

Fig. 3. The results we showed to Controls (A: Top) and PwP (B: Bottom).



Image generated by Dall-E



Tasks
8 mins



Tasks Survey
2 mins



Results
1 min



Results Survey
2 mins



Help & Support
5 mins



Help & Support Survey
2 mins



Final Survey
2 mins

Help & Support

While managing Parkinson's disease (PD) can be challenging, there are many valuable sources of information available to support people with PD and their care partners. We invite you to chat with ParkBot, search for a movement disorder specialist in your area, learn more about research-backed recommendations and tips to help enhance quality of life, and explore our up-to-date resource library.



Talk to ParkBot

Talk to an interactive chatbot that is can answer your question.



Find a Specialist

Use the MDS Movement Disorders Specialist Finder to locate a specialist near you.



Get Advice

Review evidence-based Parkinson's recommendations.



Explore Resources

Browse Parkinson's-related resources covering a range of topics.

Wasifur Rahman, Abdelrahman Abdelkader, Sangwu Lee, Phillip Yang, Md Saiful Islam, Tariq Adnan, Masum Hasan, Ellen Wagner, Sooyong Park, E Ray Dorsey, Catherine Schwartz, Karen Jaffe, Ehsan Hoque, [A User-Centered Framework to Empower People with Parkinson's Disease](#), ACM IMWUT 2024



LLM powered ChatBot

A: Answering basic question

PB

Hi, I'm ParkBot! Feel free to ask me any questions you may have.

Hello, what is parkinson's ?

PB

Parkinson's disease is a progressive neurological disorder that affects movement, including shaking, stiffness, and difficulty with walking, balance, and coordination. It can also cause problems with thinking, speaking, and emotions. For more information about Parkinson's disease, please visit: [Click Here](#)

Type your question here. Press "Enter" to ask your question.



B: Guardrail for medication questions

other illnesses, such as heart disease, which could be fatal. To learn more, please visit: [Click Here](#)

can you tell me some Medicatio and doses to take for Parkinson's ?

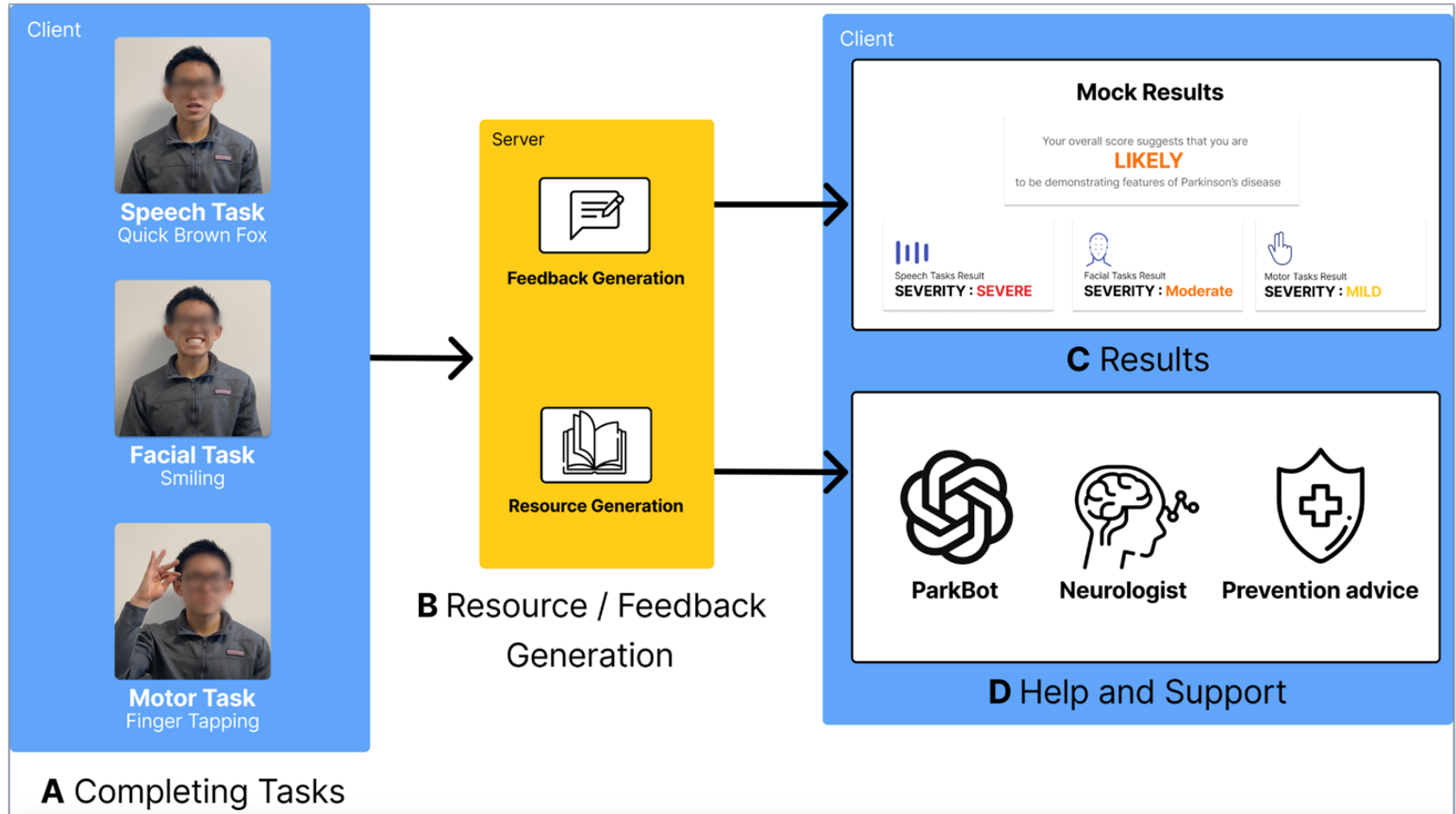
PB

I am sorry, I am not qualified to provide medical advice. Please consult your doctor or healthcare provider for more information on medications and doses for Parkinson's disease. You can find more information on medications and treatments available for Parkinson's at the following link: [Click Here](#)

Type your question here. Press "Enter" to ask your question.



Study Design

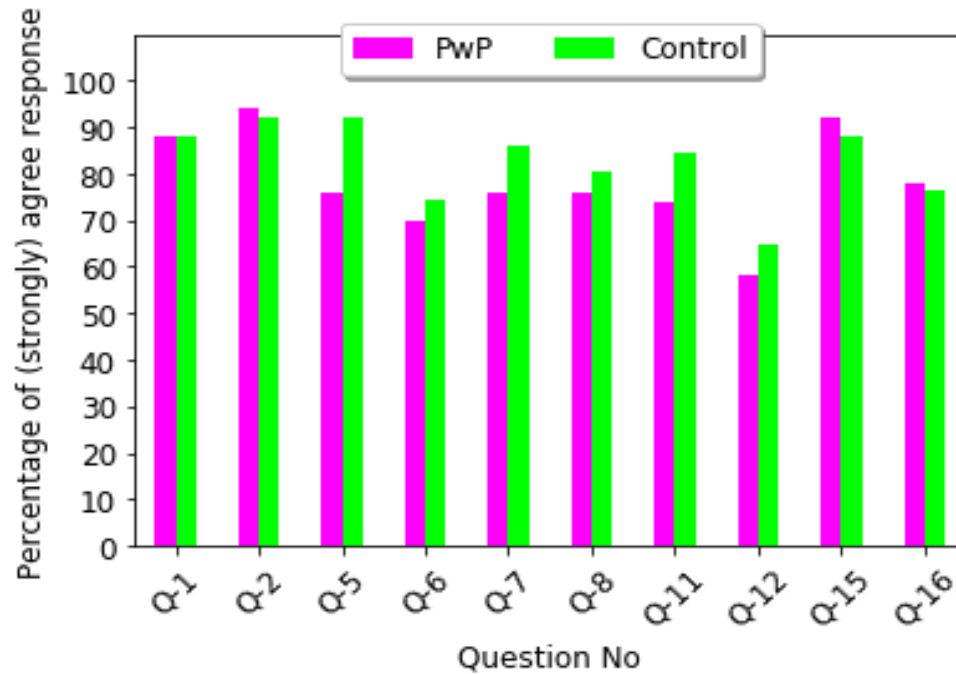




The Allan Goldberg
**Center for
Parkinson's
Wellness**

23905

84% of the participants judged our framework and the feedback mechanisms favorably.



Key Insights from User Feedback

- **Users asked for clear explanation of the screening algorithm**
 - “Explanations of what observations lead to the results.”
 - “More clarity on the ratings would be beneficial, as interpreting feedback can be challenging when unsure about the task execution.”

Users would prefer interpretable models



Key Insights from User Feedback

- **Take home report to share with doctors**
 - “Is there something we can provide to PwP to take to their neurologist?”

They want to share the results with their neurologists



Key Insights from User Feedback

- **Up-to-date ChatBot**

- “It is essential to keep the chatbot updated, which was reflected when it successfully answered a question about a recent biomarker research.”

Ensure the chatbot stays updated with the latest information and research.



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