Promote **OPEN SYSTEMS, INCENTIVES, and NORMS** to redefine how complex biological data is **GATHERED, SHARED, AND USED.**
The mPower study, Parkinson disease mobile data collected using ResearchKit

Brian M. Bot, Christine Suver, Elias Chaibub Neto, Michael Kellen, Arno Klein, Christopher Bare, Megan Doerr, Abhishek Pratap, John Wilbanks, E. Ray Dorsey, Stephen H. Friend & Andrew D. Trister
Use 2 fingers to alternately tap as fast as you can for 20 seconds.

Total Taps
101
<table>
<thead>
<tr>
<th>Traditional Measures</th>
<th>First-order Features</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Taps</td>
<td>Number of taps, Mean tapping interval, Median tapping interval, Minimum tapping</td>
</tr>
<tr>
<td></td>
<td>interval, maximum tapping interval, Standard deviation of tapping interval, Kurtosis</td>
</tr>
<tr>
<td></td>
<td>of tapping interval, Interquartile range of tapping interval, Interquartile range</td>
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<tr>
<td></td>
<td>of right button X, Range right button X, Standard deviation right button X,</td>
</tr>
<tr>
<td></td>
<td>Interquartile range of left button X, Range left button X, Standard deviation</td>
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<tr>
<td></td>
<td>left button X, Interquartile range of right button Y, Range right button Y,</td>
</tr>
<tr>
<td></td>
<td>Standard deviation right button Y, Interquartile range of left button Y, Range</td>
</tr>
<tr>
<td></td>
<td>left button Y, Standard deviation left button Y, Correlation X and Y, Skew</td>
</tr>
<tr>
<td></td>
<td>tapping interval, No-button tapping frequency</td>
</tr>
</tbody>
</table>
same medicine, different impacts

Number of Taps
Mean Tapping Interval
Median Tapping Interval

62 y old Man

Standard Deviation R Y
Range Right Y
Correlation X Y

67 y old Woman
tapping number shows effects of medication and daily variation
sharing personal thoughts on day-to-day changes
activities after first day
frequency
“Doing this is a lot of work. Send us an email now and then to let us know how it's going.”
“If you depend on us to partner with you in research, it would be good to give us feedback. ...Could you provide summary trend reports in plain language...”
thank you for joining the mPower community
working together to better manage the symptoms of Parkinson Disease

14% Reported having Parkinson Disease
86% Joined mPower as a control (no diagnosis of PD)

Age of participants

- 18-34: 57%
- 35-44: 15%
- 45-54: 10%
- 55-64: 9%
- 65 & up: 9%

78% Chose to share their coded data with other researchers worldwide
We have heard your feedback!
mPower Participant Webinar

1,098 views

Sage Bionetworks
Streamed live on Dec 19, 2015

The first mPower Parkinson Disease Study participant Webinar
Figure 4. Who do PHD users share with?

Who do you share your PHD with?

Percent of responses

- Friend
- Spouse/Partner
- Health Professional
- Other Family Members
- Sibling
- Personal Trainer or Coach
- Parent
- Member of a Social Group
- Your Child
Figure 5. Sharing with Researchers

Would you be willing to share your PHD with researchers?

Percent of responses

>75%
Figure 6. Attitudes towards anonymity of Personal Health Data

*How important is it to you that your PHD be kept anonymous?*

**Percent of responses**

- Not at all: 0
- Somewhat: 30
- Very: 20
- Extremely: >95%
Start: Jan 1, 2015

End: May 27, 2016

Download Data

Future Independent Research

Your coded study data is valuable. In addition to this study, it could be used for other research. You get to decide whether or not to share your data for other research. These screens explain more about this option.

Learn more
Qualified Researchers

With your permission, we will share your coded study data with qualified researchers worldwide. We have rules to qualify researchers. However, we do not control the research that they do with the shared data.

Learn more

Next

Sharable Data

Only coded study data are sharable. Coded study data do not include your name or email address. A random code is used instead.

Learn more

Next
identity

test

data use statement
I, _____________________*, reaffirm my commitment to the Synapse Awareness and Ethics Pledge. I will adhere to the following principles for responsible research:

<table>
<thead>
<tr>
<th>Icon</th>
<th>Statement</th>
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<tbody>
<tr>
<td>![No Fingerprints]</td>
<td>I WILL NOT RE-IDENTIFY</td>
</tr>
<tr>
<td>![No Up Arrow]</td>
<td>I WILL NOT SHARE</td>
</tr>
<tr>
<td>![No Dollar Sign]</td>
<td>I WILL NOT USE FOR ADVERTISING</td>
</tr>
<tr>
<td>![Safe]</td>
<td>I WILL KEEP SECURE</td>
</tr>
<tr>
<td>![Locked Computer]</td>
<td>I WILL PROTECT PRIVACY</td>
</tr>
<tr>
<td>![Unlock]</td>
<td>I WILL PUBLISH OPEN ACCESS</td>
</tr>
<tr>
<td>![Phone]</td>
<td>I WILL REPORT ANY BREACHES</td>
</tr>
<tr>
<td>![Medal]</td>
<td>I WILL CREDIT PARTICIPANTS</td>
</tr>
<tr>
<td>![Scales]</td>
<td>I WILL FOLLOW THE LAW</td>
</tr>
</tbody>
</table>

* Printed name  
Signature  
Date

To complete this form:
1. Enter your name (see *)
2. Mark your initials on the line in the upper right corner of each box (9 times, total)
3. Sign and date
## mPower six month data release

<table>
<thead>
<tr>
<th>task name</th>
<th>type of task and schedule</th>
<th>unique participants</th>
<th>unique tasks</th>
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</thead>
<tbody>
<tr>
<td>demographics</td>
<td>survey - once</td>
<td>6,805</td>
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<td>survey - monthly</td>
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<td>PDQ8</td>
<td>survey - monthly</td>
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<td>1,641</td>
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<tr>
<td>memory</td>
<td>activity - t.i.d.</td>
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<td>78,887</td>
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<td>voice</td>
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<td>walking</td>
<td>activity - t.i.d.</td>
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<td>35,410</td>
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</tbody>
</table>
Parkinson mHealth research community

study data released before any primary publication
60+ independent ‘qualified researchers’
working towards building a PD research community

MIT
The Ohio State University
University of Otago
University of Texas Health Science Center
Istanbul Sehir University
University of Iowa
University of Virginia
University of Toronto
Johns Hopkins University
Vanderbilt University
University of Rochester
McGill University
Xi'an Jiaotong University
University of Washington
Harvard University

Parkinson’s Disease Foundation
Eli Lilly
AstraZeneca
Apple
Verily
Intel
Infocepts
Posit Science
please @ me

john.wilbanks@sagebase.org
http://sagebase.org/platforms/governance
@wilbanks