Sage
BIONETWORKS
BIONETWORKS 8

Promote ***OPEN SYSTEMS***, ***INCENTIVES***, and ***NORMS*** to redefine how complex biological data is ***GATHERED***, ***SHARED***, AND ***USED.***

SCIENTIFIC DATA

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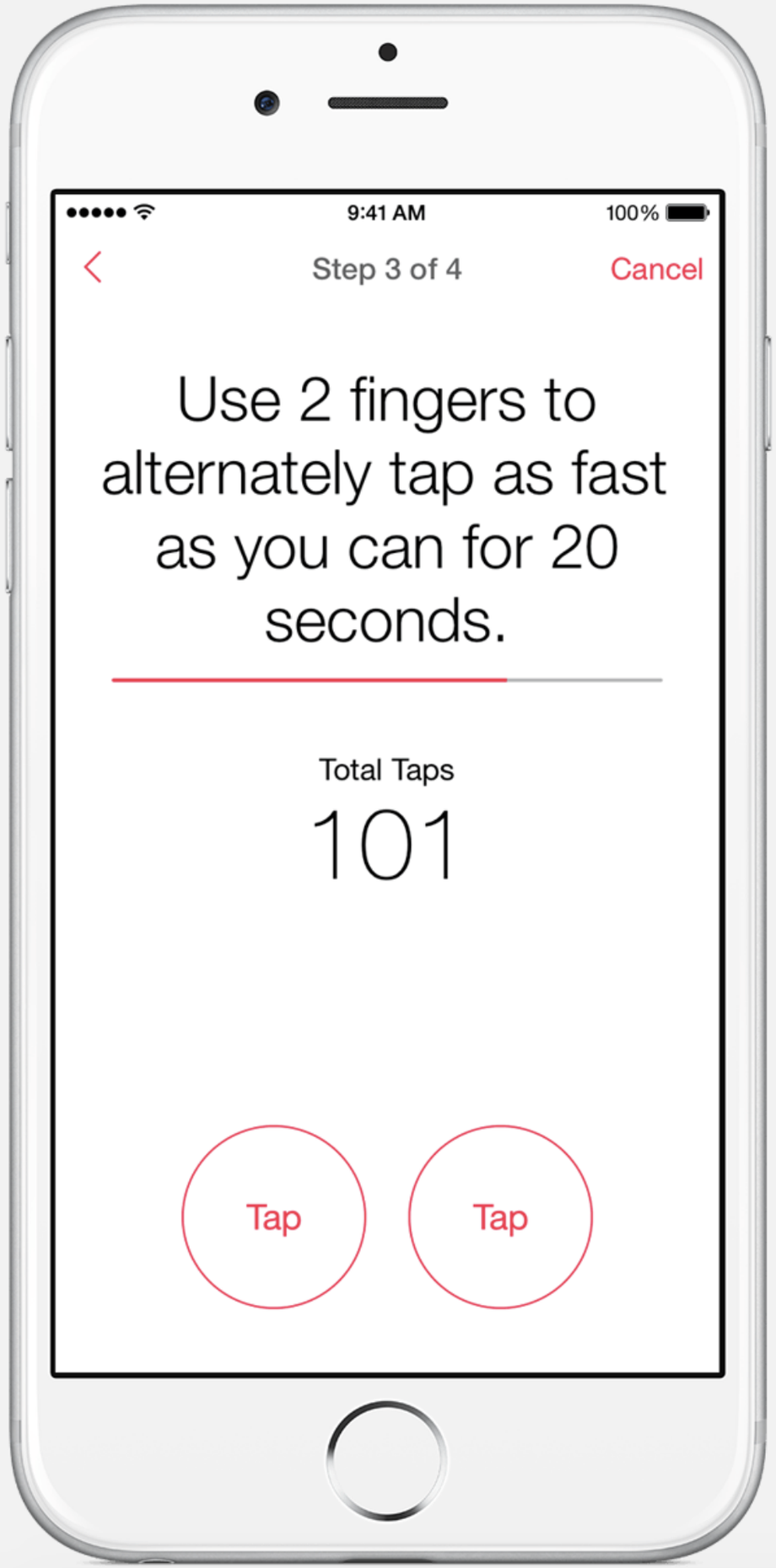
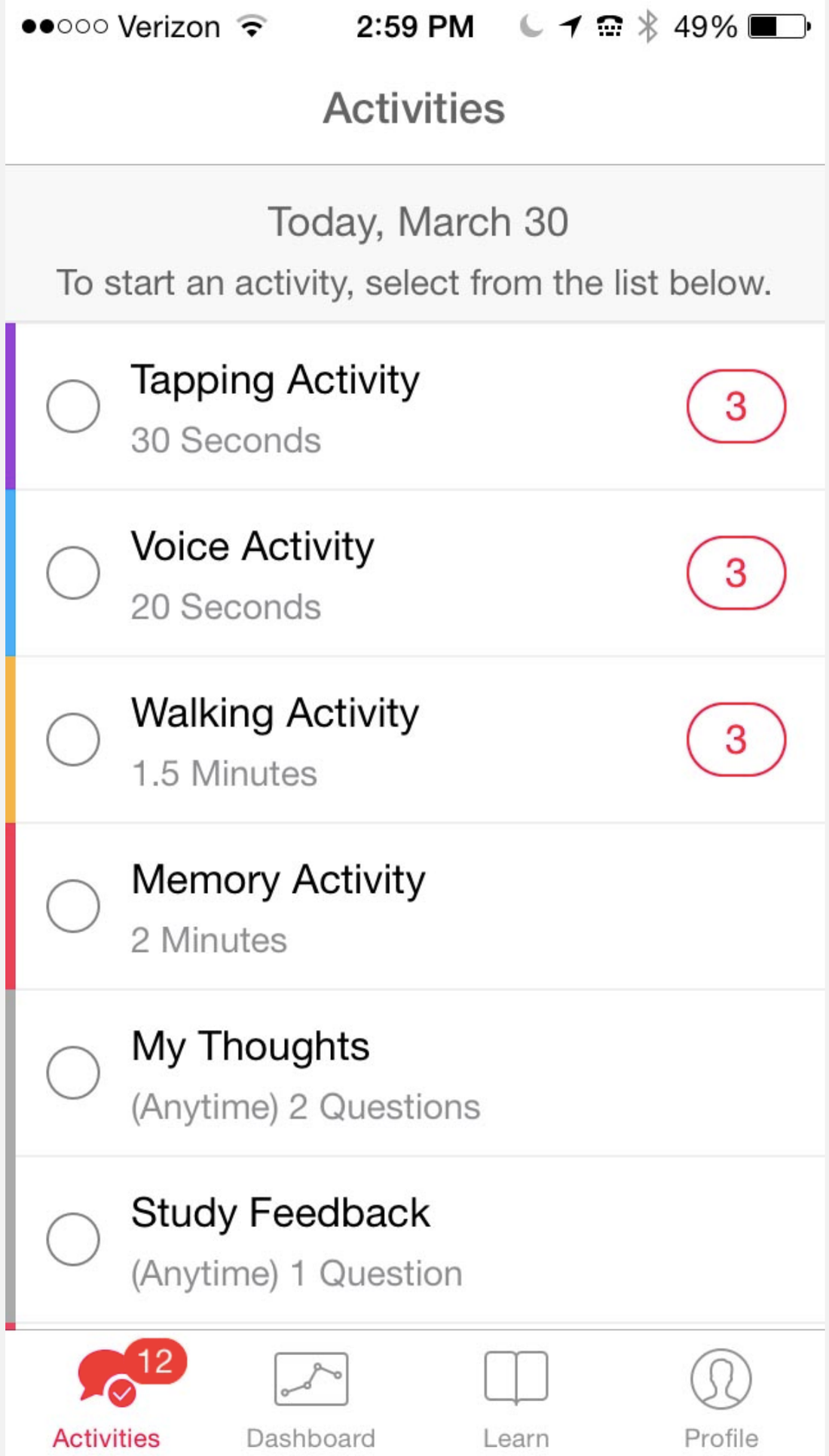
SCIENTIFIC DATA | DATA DESCRIPTOR OPEN

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

data generation

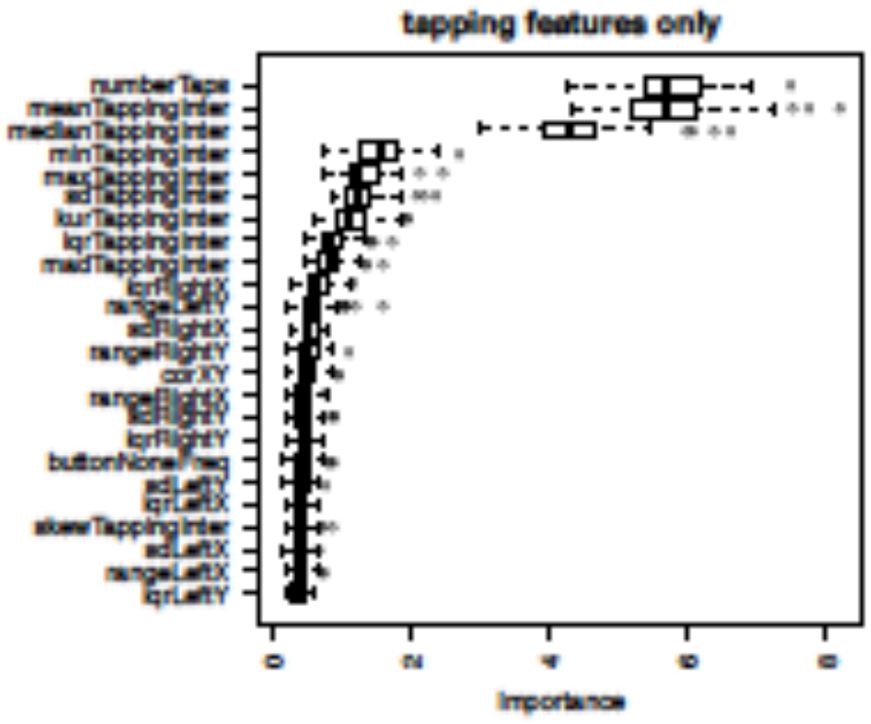

9:41 AM
100%
Step 3 of 4
Cancel
Use 2 fingers to alternately tap as fast as you can for 20 seconds.
Total Taps
101
Tap
Tap


Verizon
2:59 PM
49%
Activities
Today, March 30
To start an activity, select from the list below.
Tapping Activity
30 Seconds
3
Voice Activity
20 Seconds
3
Walking Activity
1.5 Minutes
3
Memory Activity
2 Minutes
My Thoughts
(Anytime) 2 Questions
Study Feedback
(Anytime) 1 Question
12
Activities
Dashboard
Learn
Profile

high-dimensional data

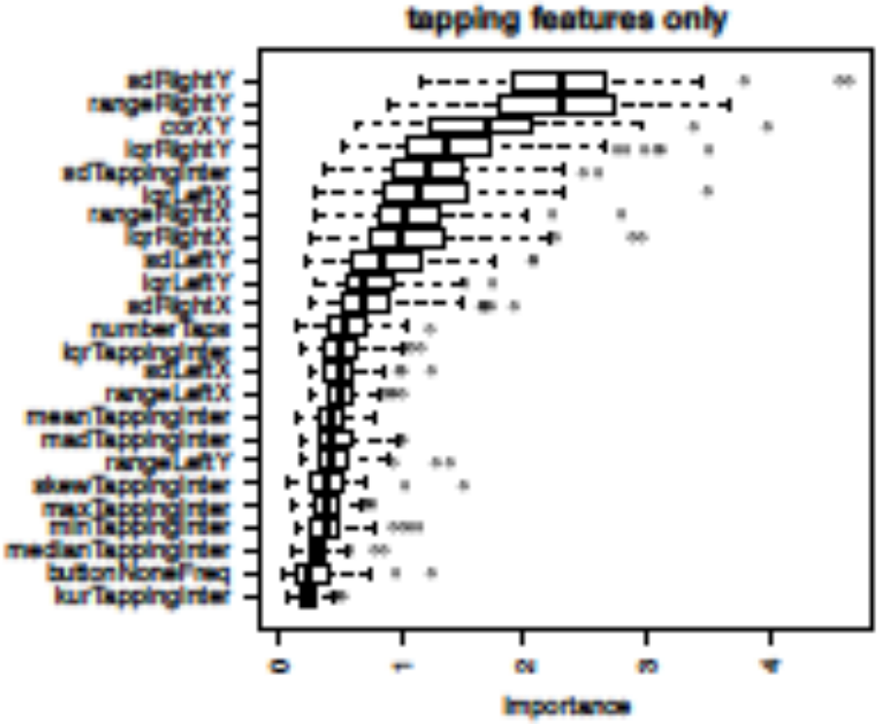
Traditional Measures	First-order Features
Number of Taps	Number of taps, Mean tapping interval, Median tapping interval, Minimum tapping interval, maximum tapping interval, Standard deviation of tapping interval, Kurtosis of tapping interval, Interquartile range of tapping interval, Interquartile range of right button X, Range right button X ,Standard deviation right button X, Interquartile range of left button X, Range left button X ,Standard deviation left button X, Interquartile range of right button Y, Range right button Y ,Standard deviatiion right button Y, Interquartile range of left button Y, Range left button Y ,Standard deviation left button Y, Correlation X and Y, Skew tapping interval, No-button tapping frequency

same medicine, different impacts



Number of Taps
Mean Tapping Interval
Median Tapping Interval

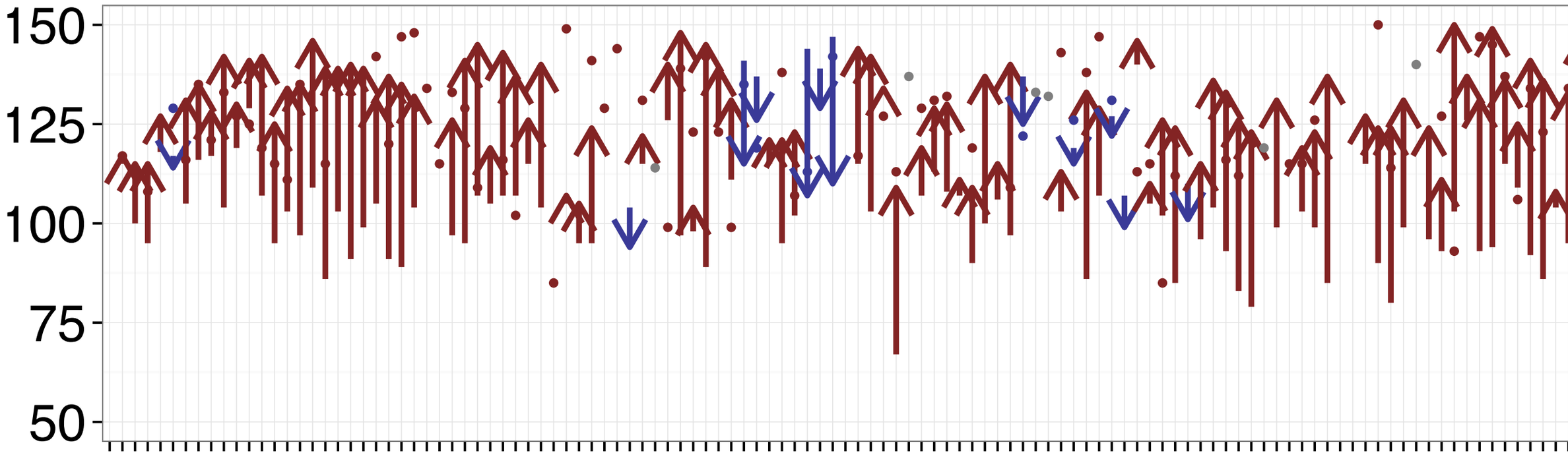
62 y old Man

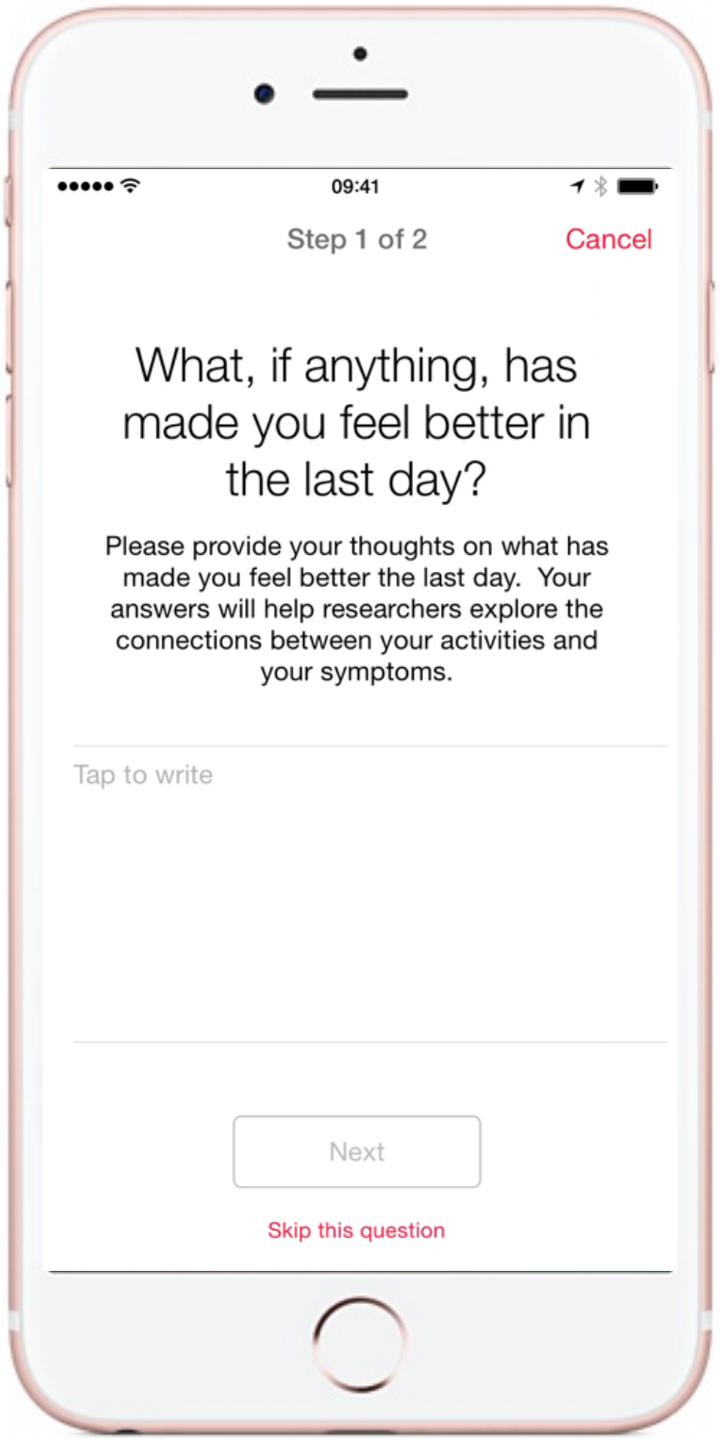


Standard Deviation R Y
Range Right Y
Correlation X Y

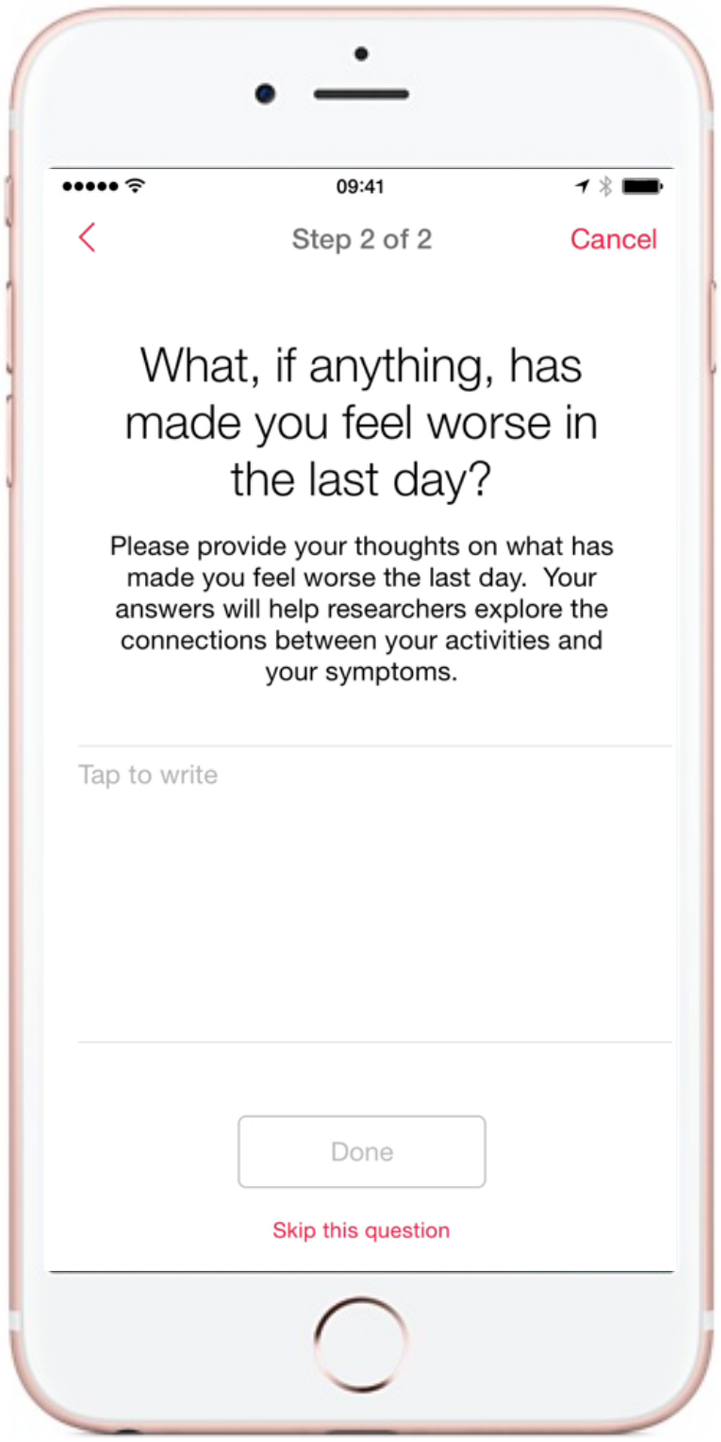
67 y old Woman

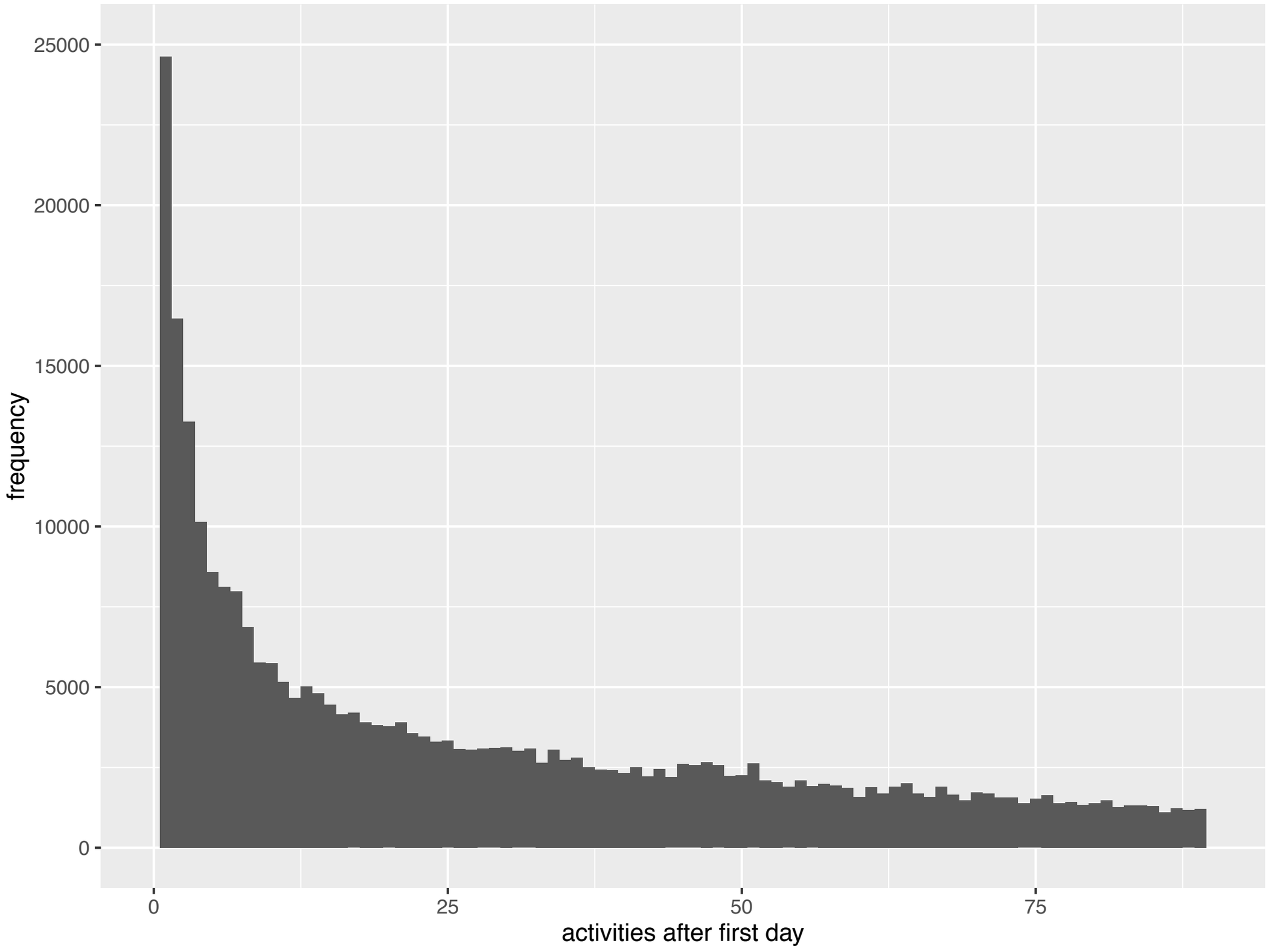
tapping number shows effects of medication and daily variation





sharing personal thoughts on day-to-day changes




25000
20000
15000
10000
5000
0
frequency
0
25
50
75
activities after first day

“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

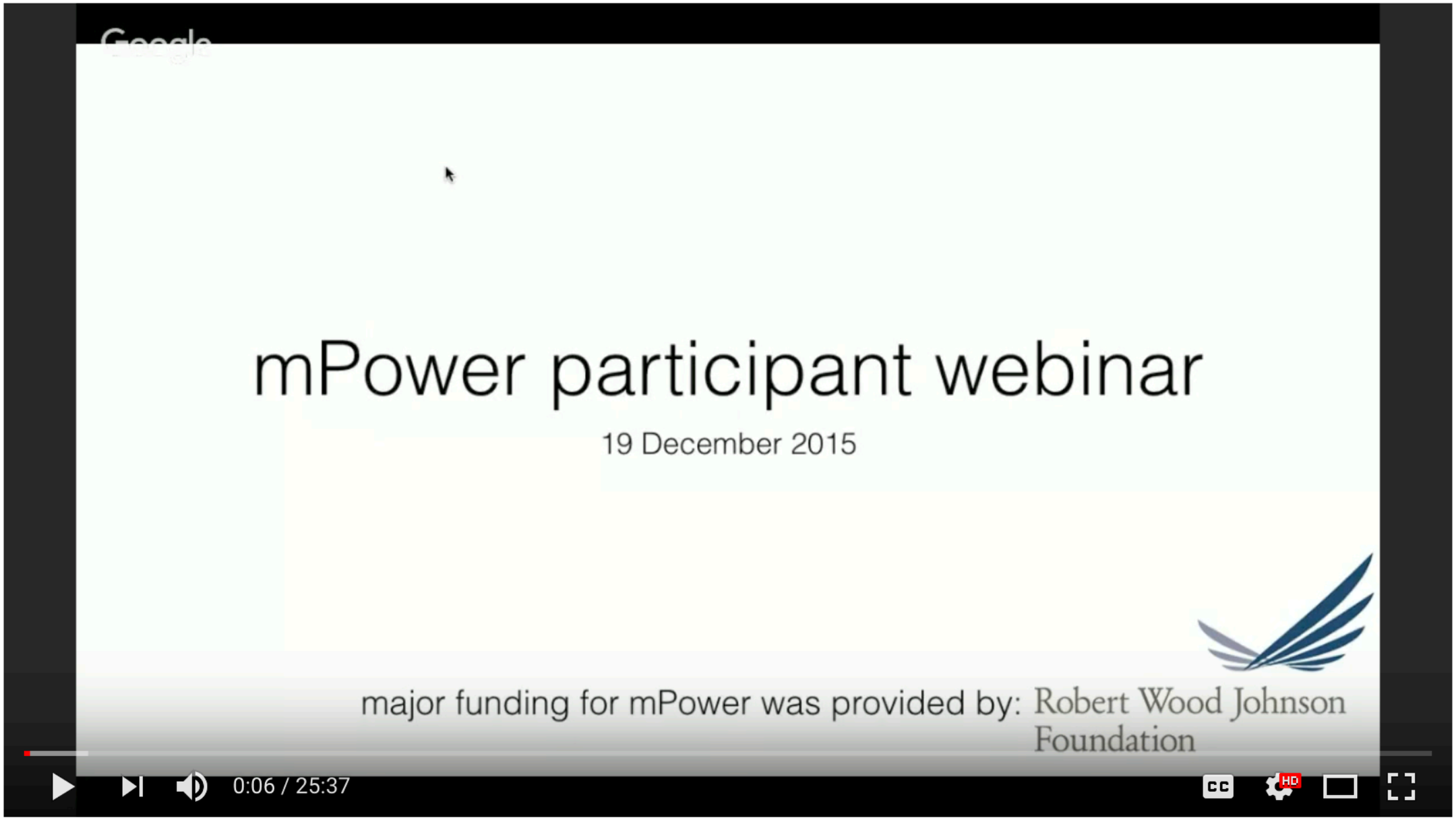
86%
Joined mPower as a control (no diagnosis of PD)

Age of participants

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

78%
Chose to share their coded data with other researchers worldwide

We have **heard** your **feedback!**



mPower Participant Webinar

1,098 views

LIKE DISLIKE SHARE

Sage Bionetworks
Streamed live on Dec 19, 2015

SUBSCRIBE

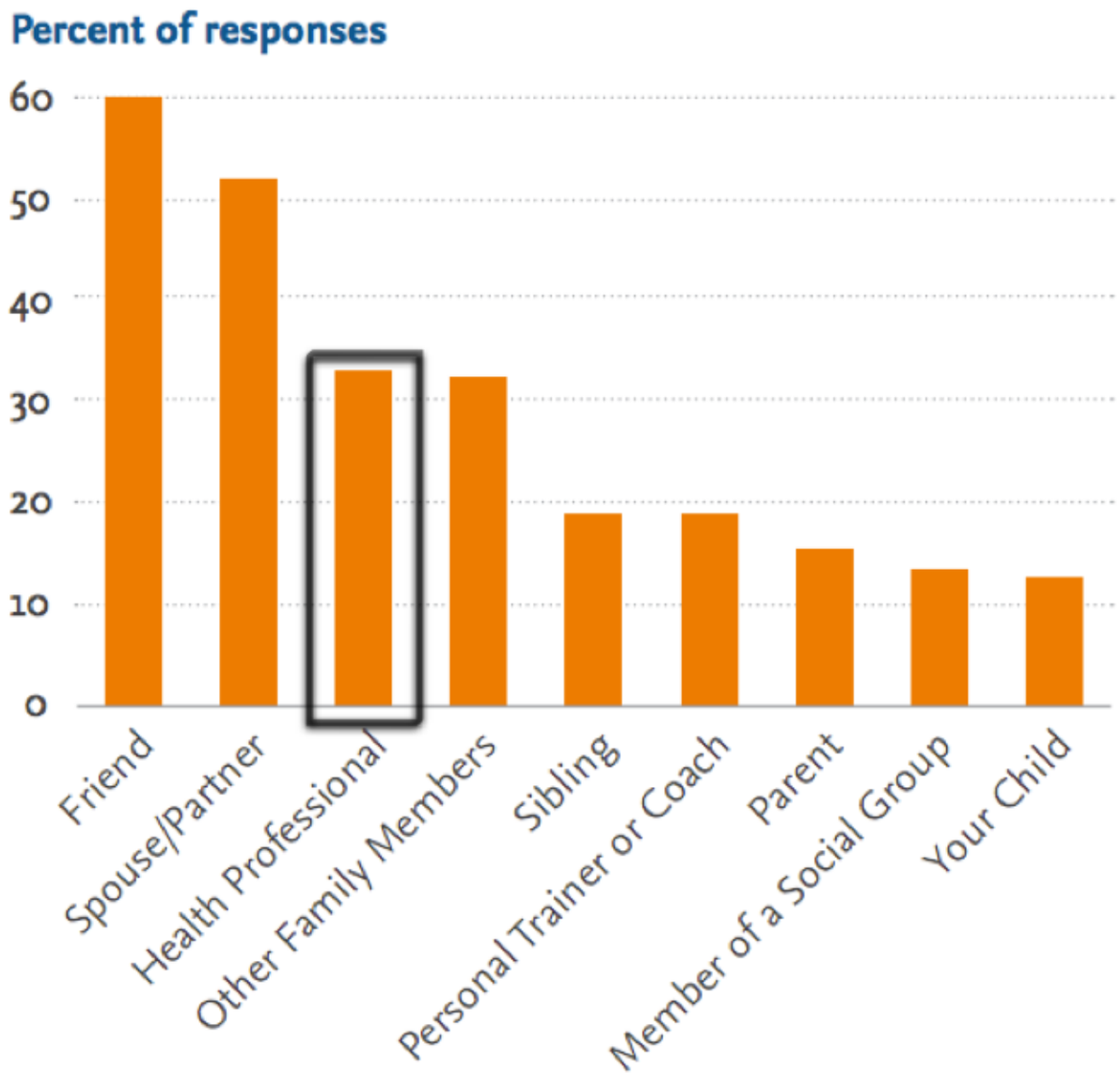
The first mPower Parkinson Disease Study participant Webinar

Health Data Exploration project

Robert Wood Johnson Foundation

Figure 4. **Who do PHD users share with?**

Who do you share your PHD with?

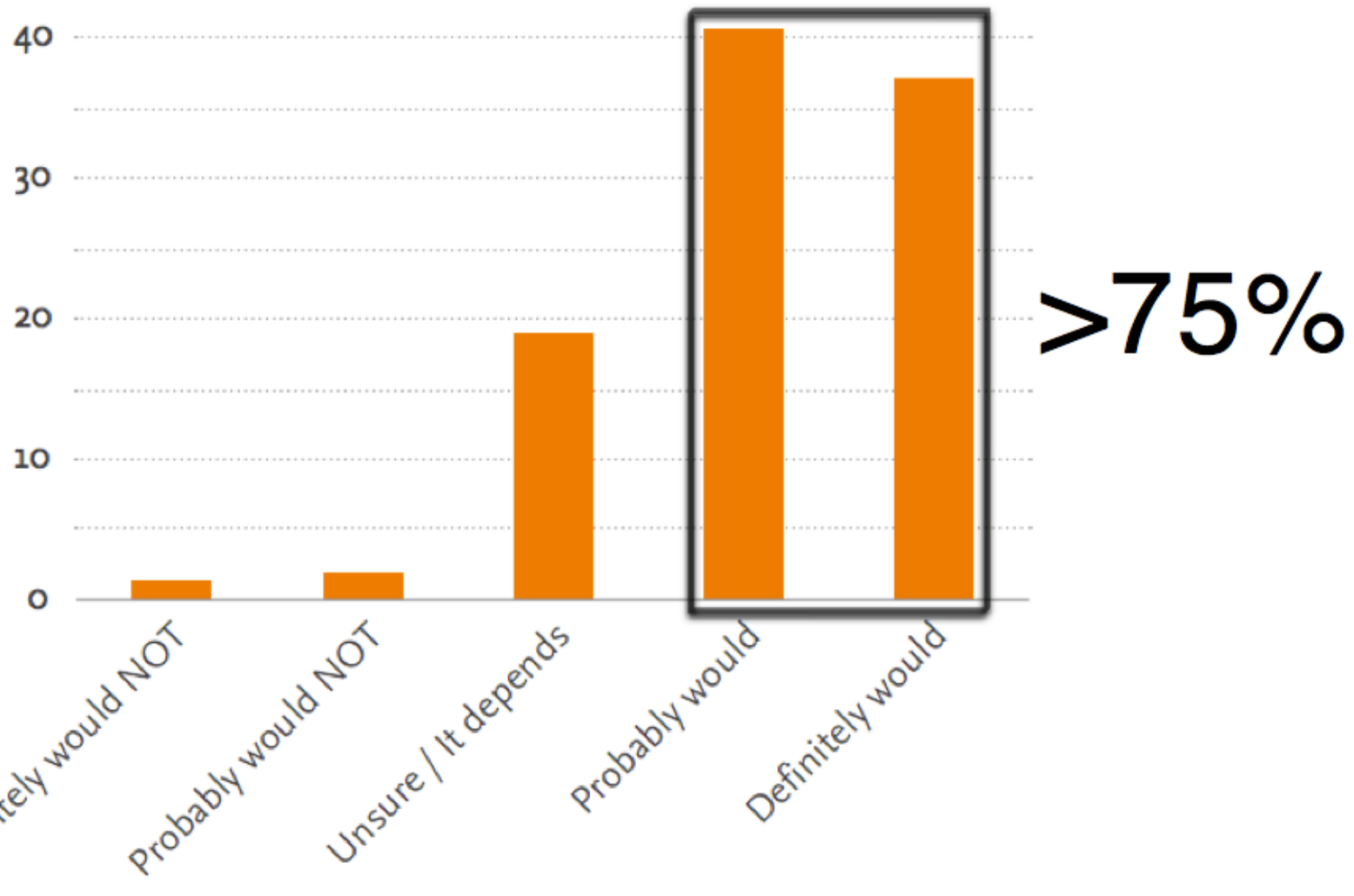


Health Data Exploration project

Robert Wood Johnson Foundation

Figure 5. **Sharing with Researchers**

Would you be willing to share your PHD with researchers?

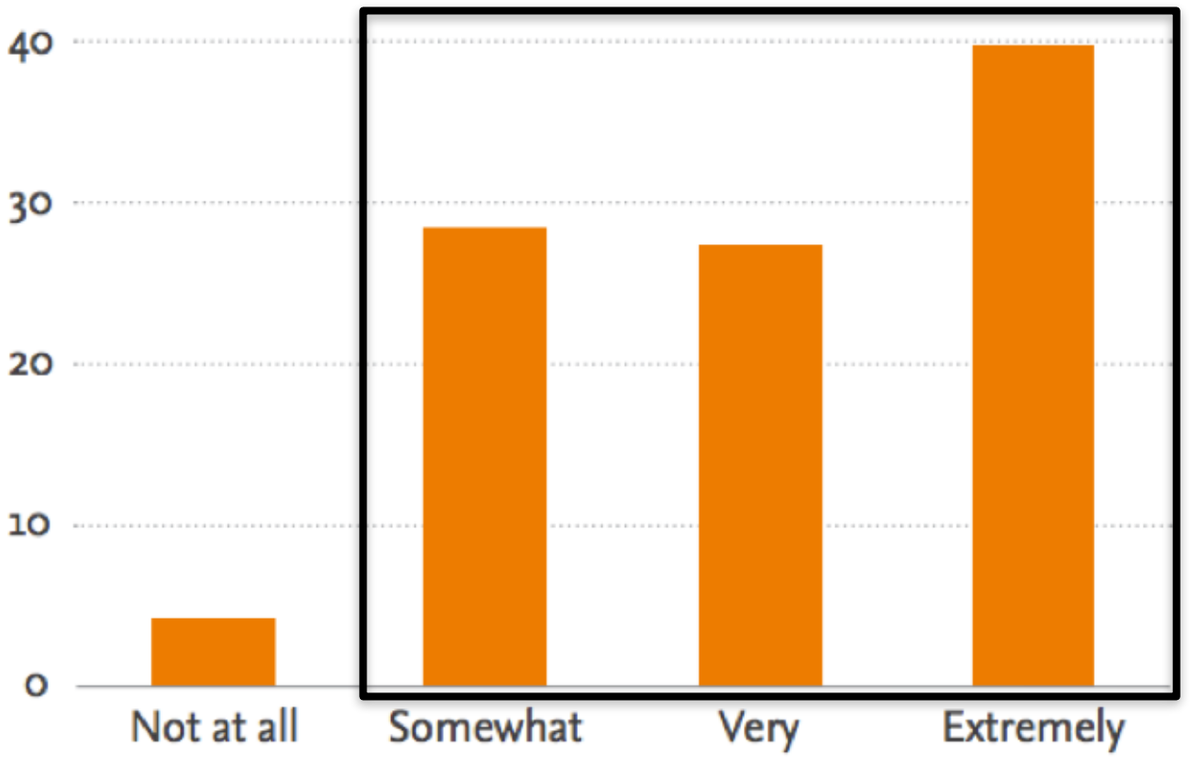


Health Data Exploration project

Robert Wood Johnson Foundation

Figure 6. **Attitudes towards anonymity of Personal Health Data**

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



>95%

●●○○○ AT&T Wi-Fi 1:36 PM 100%

Download Data

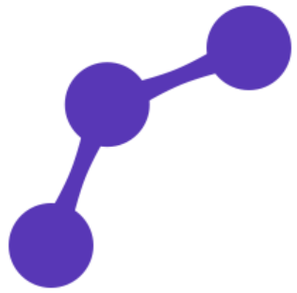
Start Jan 1, 2015

End May 27, 2016

Download Data

●●○○○ AT&T Wi-Fi 1:29 PM 100%

Cancel



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

Next

●●○○○ AT&T Wi-Fi 1:29 PM 100%

Cancel

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

●●○○○ AT&T Wi-Fi 1:29 PM 100%

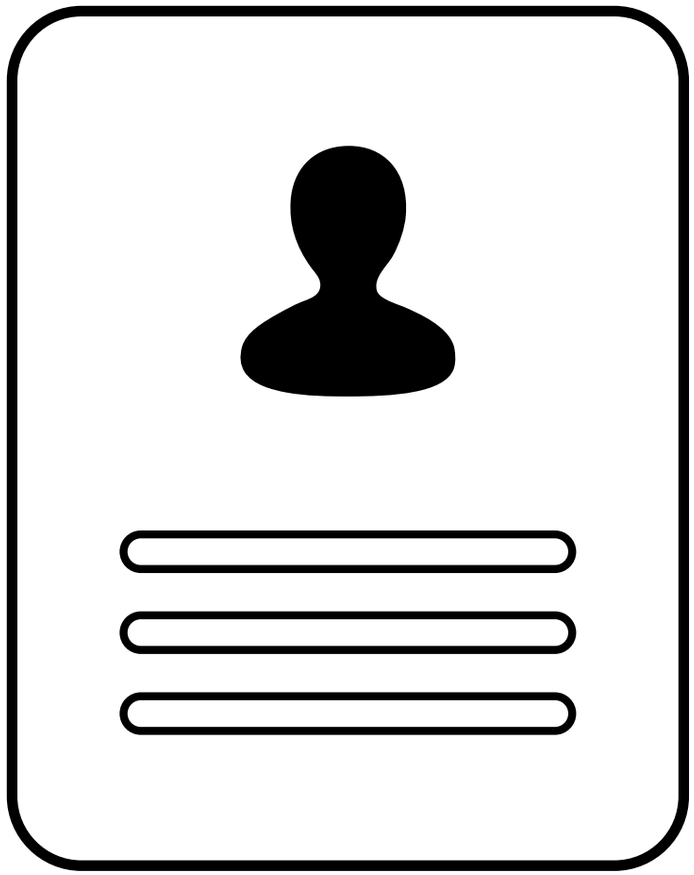
Cancel

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.

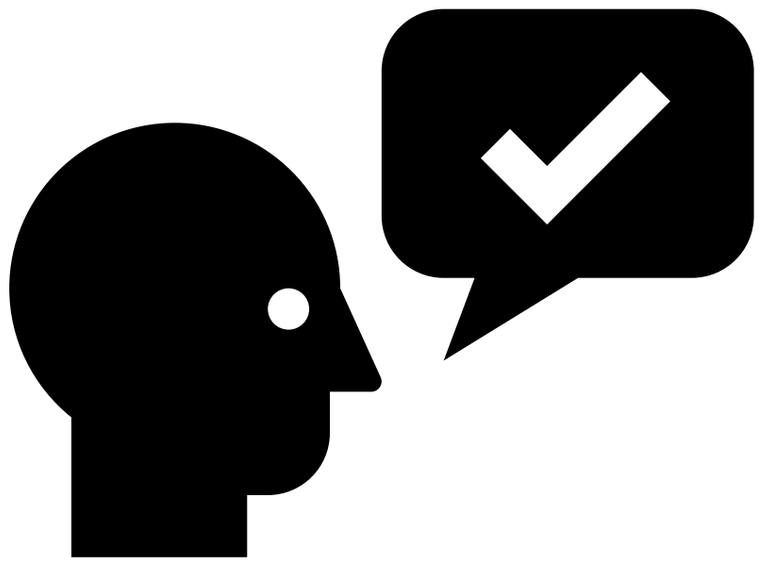
Learn more

Next



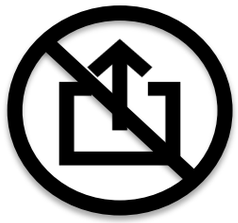
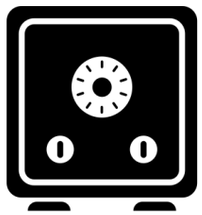
identity

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:

____ **I WILL NOT RE-IDENTIFY**	 ____ **I WILL NOT SHARE**	____ **I WILL NOT USE FOR ADVERTISING**
 ____ **I WILL KEEP SECURE**	____ **I WILL PROTECT PRIVACY**	____ **I WILL PUBLISH OPEN ACCESS**
____ **I WILL REPORT ANY BREACHES**	____ **I WILL CREDIT PARTICIPANTS**	____ **I WILL FOLLOW THE LAW**

_____ *** 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

task name	type of task and schedule	unique participants	unique tasks
demographics	survey - once	6,805	6,805
MDS-UPDRS	survey - monthly	2,024	2,305
PDQ8	survey - monthly	1,334	1,641
memory	activity - t.i.d.	968	8,569
tapping	activity - t.i.d.	8,003	78,887
voice	activity - t.i.d.	5,826	65,022
walking	activity - t.i.d.	3,101	35,410

data generation

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

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