A SCIENTIST OF THE FUTURE RECORDS EXPERIMENTS WITH A TINY CAMERA FITTED WITH UNIVERSAL-FOCUS LENS. THE SMALL SQUARE IN THE EYEGLASS AT THE LEFT SIGHTS THE OBJECT.

AS WE MAY THINK

A TOP U.S. SCIENTIST FORESEES A POSSIBLE FUTURE WORLD IN WHICH MAN-MADE MACHINES WILL START TO THINK

by VANNEVAR BUSH

DIRECTOR OF THE OFFICE OF SCIENTIFIC RESEARCH AND DEVELOPMENT
Condensed from the Atlantic Monthly, July 1945
"Professionally our methods of transmitting and reviewing the results of research are generations old and by now are totally inadequate for their purpose."
what is the “adjacent possible?”
nearly 200 million smart phone users in US
A software framework made specifically for medical research
ResearchKit

It’s open source. So the world can make the most of it.
mPower helps decipher Parkinson’s disease.

The variability in Parkinson’s disease symptoms has left many questions unanswered. So the University of Rochester and Sage Bionetworks created the mPower app to precisely measure data such as dexterity, balance, memory, and gait. This information could help researchers better understand how various symptoms are connected to Parkinson’s disease. In turn, participants could start to recognize their own signs and symptoms.

**First 6 months**

- **16,585** participants consented
- **14,684** participants enrolled
- **9,520** agreed to ‘share broadly’
- **1,087** self reported PD diagnosis
mPower activities

motor initiation

gait/balance

hypophonia

memory

Tapping Interval Test
Rest your phone on a flat surface. Then use two fingers on the same hand to alternately tap the buttons that appear. Keep tapping for 20 seconds and time your taps to be as consistent as possible. Tap Get Started to begin the test.

Gait and Balance Test
This test measures your gait and balance as you walk and stand still. To complete this test, you’ll need to put your phone in your pocket and connect headphones to follow audio instructions.

Say “Aaaaah” into the microphone for as long as you can.

Spatial Memory Test
This test measures your spatial memory by showing you patterns and asking you to recall and repeat them.

data generation
high-dimensional data

<table>
<thead>
<tr>
<th>Traditional Measures</th>
<th>First-order Features</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number of Taps</strong></td>
<td>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 deviation 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</td>
</tr>
</tbody>
</table>
same medicine, different impacts

62 y old Man

67 y old Woman
tapping number shows effects of medication and daily variation
22,000 unstructured text comments
mPower six month data release

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
analytical challenges

unbiased, consistent, and rigorous method assessment

sampling of a space of diverse methods
analytical challenges

benchmark methods for the processing of sensor data for development of digital signatures reflective of Parkinson's Disease
Life Cycle of a Digital Health Research Study

**Design**
- User Research, Study Design
- Iterative UX/UI Co-Design
- Cross-Platform Development (RK/RS)

**Development**
- Bridge Study Manager
- Synapse Data Hosting
- Collaborative Analyses on Synapse

**Data Governance**
- eConsent
- IRB Review
- Recruitment

**Data Management**
- Bridge SDKs, Bridge APIs
- Qualifed Researcher Data Portal

**Data Analysis**
- Sage Design System
- DREAM Challenge
Weekly Body Map Summaries
Congrats, insight is unlocked!

The Body Map shows how an individual’s experience with daily life can be visualized in different parts of the body. For example, some people are more likely to develop headaches when they are distressed, whereas others are more likely to feel the effects in their back or stomach.

Mar 23 - Mar 29 2018

Effects of close others
Being surrounded by close others often buffers us from stress reactivity. How does being surrounded by close others affect your systolic blood pressure (SBP) responses?

Bar chart showing:
- Alone
- Strangers
- Friends
- Family
The undersigned, Antonio Benino, having been more than twenty-five years of age, native of Cerceda, in the province of Corina, the son of Manuel Benino and Josefa Castro, here states by these presents, being in the enjoyment and exercise of his own very free will, that he consents to submit himself to experiments for the purpose of determining the methods of transmission of yellow fever, made upon his person by the Commission appointed for this purpose by the Secretary of War of the United States, and that he gives his consent to undergo the said experiments for the reasons and under the conditions below stated.

The undersigned understands perfectly well that in case of the development of yellow fever in him, that he endangers his life to a certain extent but it being entirely impossible for him to avoid the infection during his stay in this island, he prefers to take the chance of contracting it intentionally in the belief that he will receive from the said Commission the greatest care and the most skillful medical service.

It is understood that at the completion of these experiments, within two months from this date, the undersigned will receive the sum of $100 in American gold and that in case of his contracting yellow fever...
pre-existing form, would probably first of all, however slightly, in bodily structures: if so, whether the variations are transmitted in accordance with the laws which prevail within a species, are the variations the result, as far as it allows us to judge, of the same general causes? In some general laws, as in the case of correlation, the inherited effects of subject to similar malconformation of fossils, of reduplication of his anomalies, reversion to it might also naturally be...
treat IC as a design opportunity

- **Navigation**

- **Visual Information area**
  Graphics demonstrate and reinforce the information provided in text.

- **Main Concept**

- **Text Information area**

- **Learn more links**
  Opens to detailed text from the consent document.

- **Instruction area**
tell the story of the study.

Welcome

The research

Your Data

impact on your life

- Issues

What is involved

Your rights

Potential risks and benefits

Comprehension- Review & Consent
let the participant decide on openness, not the scientist.
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
participants and public get to see the users / uses.

**Researcher:** Siamak Sorooshyanari (profile)

**ORCID:** http://orcid.org/0000-0002-1172-5291

**Affiliation:** Posit Science

**Intended Data Use Statement (accepted on 2016-06-05):**

I would like to use the mPower PDQ8 data in assessing our SVM-based algorithm's capability of detecting whether a PD subject is depressed/not-depressed based on their voice characteristics. I would undertake this study by running the voice samples of the PD subjects through the PRAAT and openSMILE code that I've both developed and attained. This collective code has the capability of providing over 1000 metrics per voice sample. The resultant metrics along with the behavioral marker of the subject being depressed/not-depressed would be input to my support vector machine (SVM) algorithm which I've coded in R. The SVM would be trained on a portion of the data that I will dub "training data" and its performance will be evaluated on a portion of the data that I will dub "test data." These two pools will be variable parameters which will be adapted as part of my study and as I get acquainted with the mPower voice and PDQ8 data. In effect, the output of the voice processing code will be the features for the SVM and the PDQ8 will be the associated labels. Since SVM is a supervised learning technique both voice and mood data are required.

One of my hypotheses is that our algorithm and classifier will be able to accurately (e.g., ~65% accuracy rate) differentiate among PD subjects who are depressed versus those that are not depressed. Another hypothesis is that there will be high correlation between the voice metrics that we have collected for our (very limited number of) major depressive disorder (MDD) subjects and the mPower PD subjects. The prospects of such a technique for the detection of depression as well as its monitoring are immense. The collection and analysis of speech is non-invasive and a method which is inexpensive and relatively easy to implement and repeat among subjects. This has valuable implications for helping clinicians identify, monitor, and help prospectively depressed subjects before their condition exacerbates.

**Researcher:** Eyal Peleg (profile)

**ORCID:** http://orcid.org/0000-0001-7331-8579

**Affiliation:** Ben Gurion University

**Intended Data Use Statement (accepted on 2016-06-06):**

I am a member of the Advanced Analytics unit at Intel, working for a group that specializes in the Parkinson Disease domain. In a collaboration with the Michael J. Fox foundation, we are developing a platform that aims at assisting patients suffering from Parkinson's disease.

Moreover, I am a MSc student for Software Engineering in the Ben Gurion University, majoring in Machine Learning applications.

My research will focus on classifying patients according to medications consumption effects on tasks performance and later on extracting features which are conducive to this effect.
governance via open source

iconographic representations of key concepts in informed consent
The future of health begins with All of Us

The All of Us Research Program is a historic effort to gather data from one million or more people living in the United States to accelerate research and improve health. By taking into account individual differences in lifestyle, environment, and biology, researchers will uncover paths toward delivering precision medicine.
FIG. 1 – Centralized, Decentralized and Distributed Networks
centralization seems to be associated with the cloud. so how do we network the centralized hubs?
Sage mHealth study bootstrap

Bridge back-end study manager
data management on Synapse
pro bono consulting (20 hrs each)
- design
- engineering
- data governance / eConsent
- data science

qualified researcher program
**Successful Catalyst Applicants**

- Study overview
- Prototype app or initial wireframes
- Access to app engineering resources
- Access to ethical oversight

www.sagebionetworks.org/research-projects/catalyst-program/
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