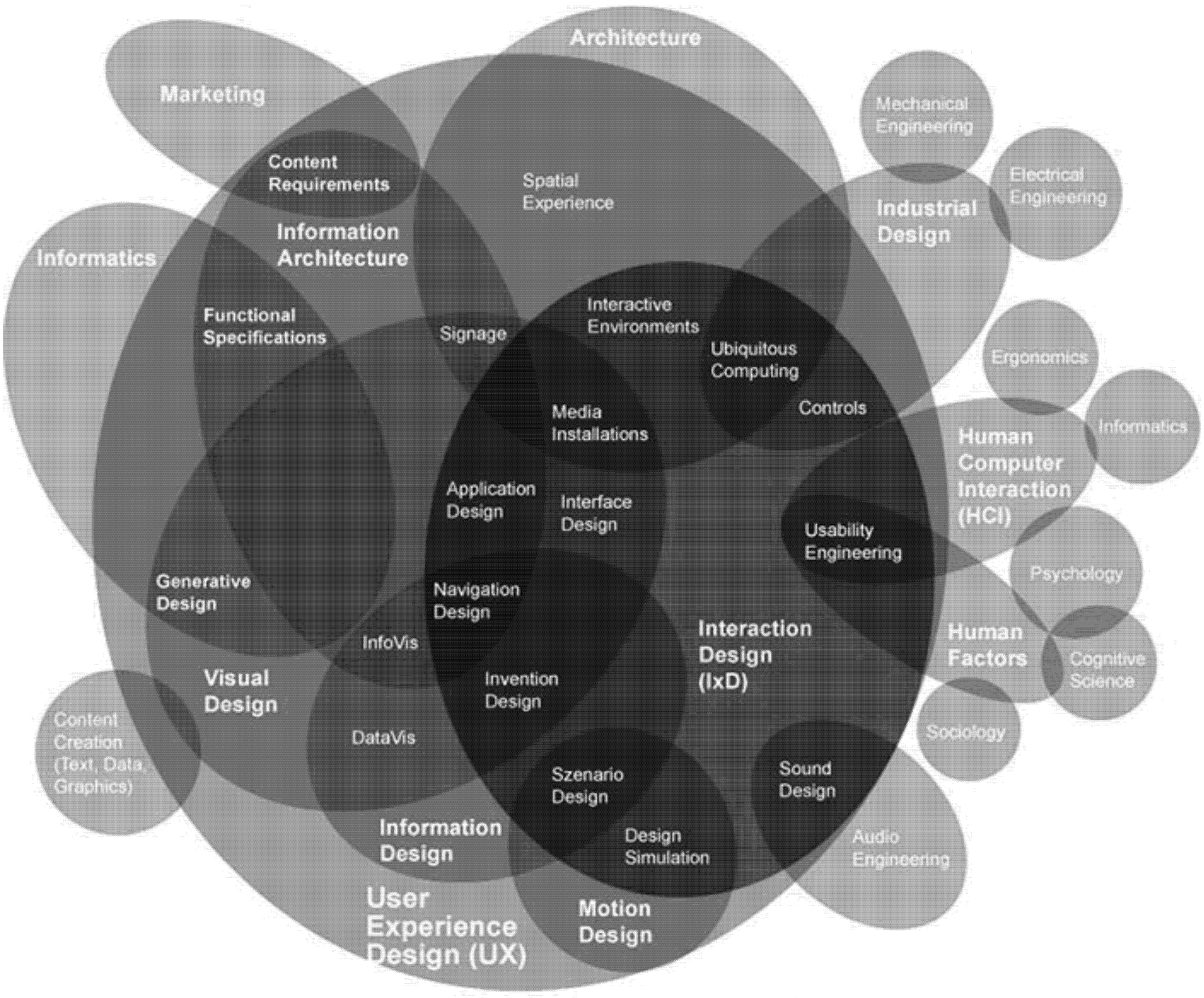
Sage Bionetworks

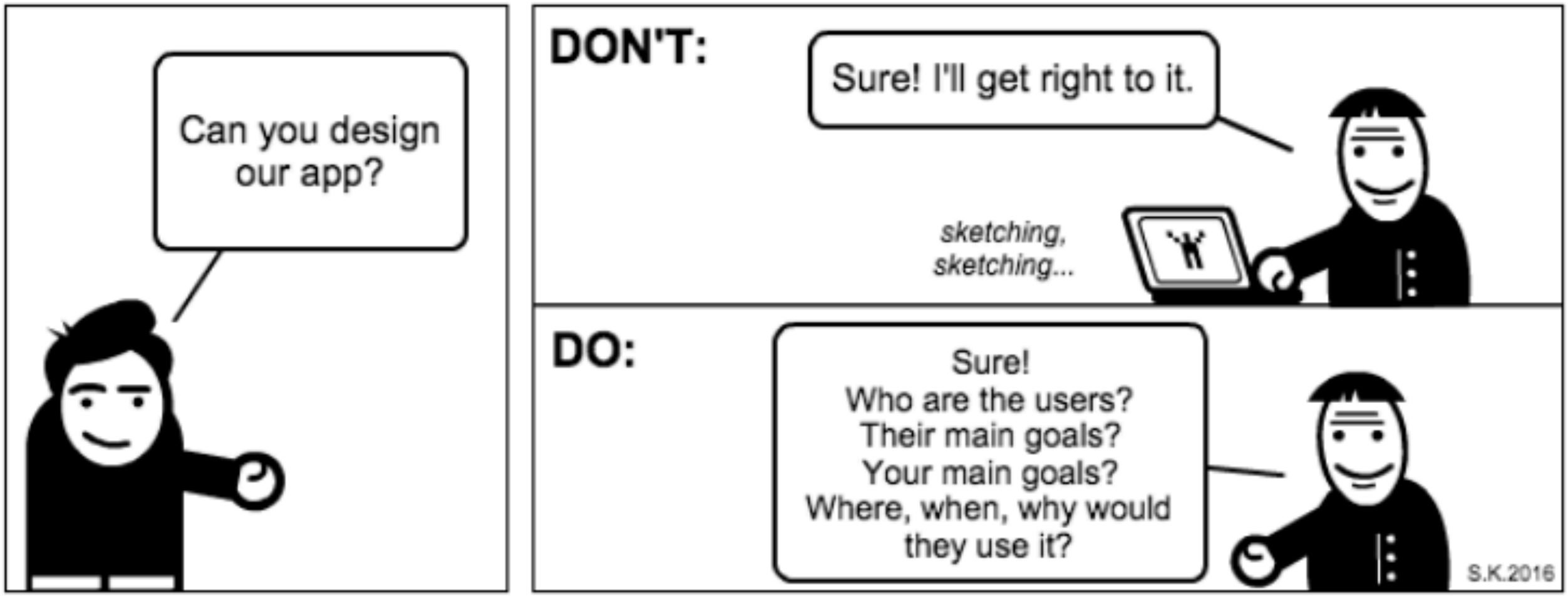
Promote ***OPEN SYSTEMS***, ***INCENTIVES***, and ***NORMS*** to redefine how complex biological data is ***GATHERED***, ***SHARED***, AND ***USED.***

METHODS are often de-prioritized in the search for ***RESULTS***.



Copyright :**envis precisely** (2009)
based on »The Disciplines of User Experience« by Dan Saffer (2008)
www.kickerstudio.com/blog/2008/12/the-disciplines-of-user-experience

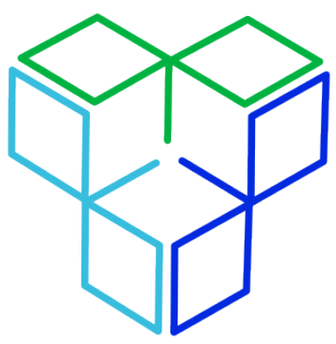
“While interaction design has an interest in form (similar to other design fields), its main area of focus rests on behavior.”



http://stripgenerator.com/strip/982042/starting-a-design-project/view/all/

1.

the technology wave means we’re going to have to deal with people as…well, people.



“Investigators will meet annually in-person with each participant to assess and record progression … every six months, the team will conduct phone and mail surveys regarding diagnosis, medications, and other impacts of the disease…”

SCIENTIFIC DATA

Home | Archive | About ▼ | For Authors ▼ | For Referees | Data Policies ▼ | Collections ▼

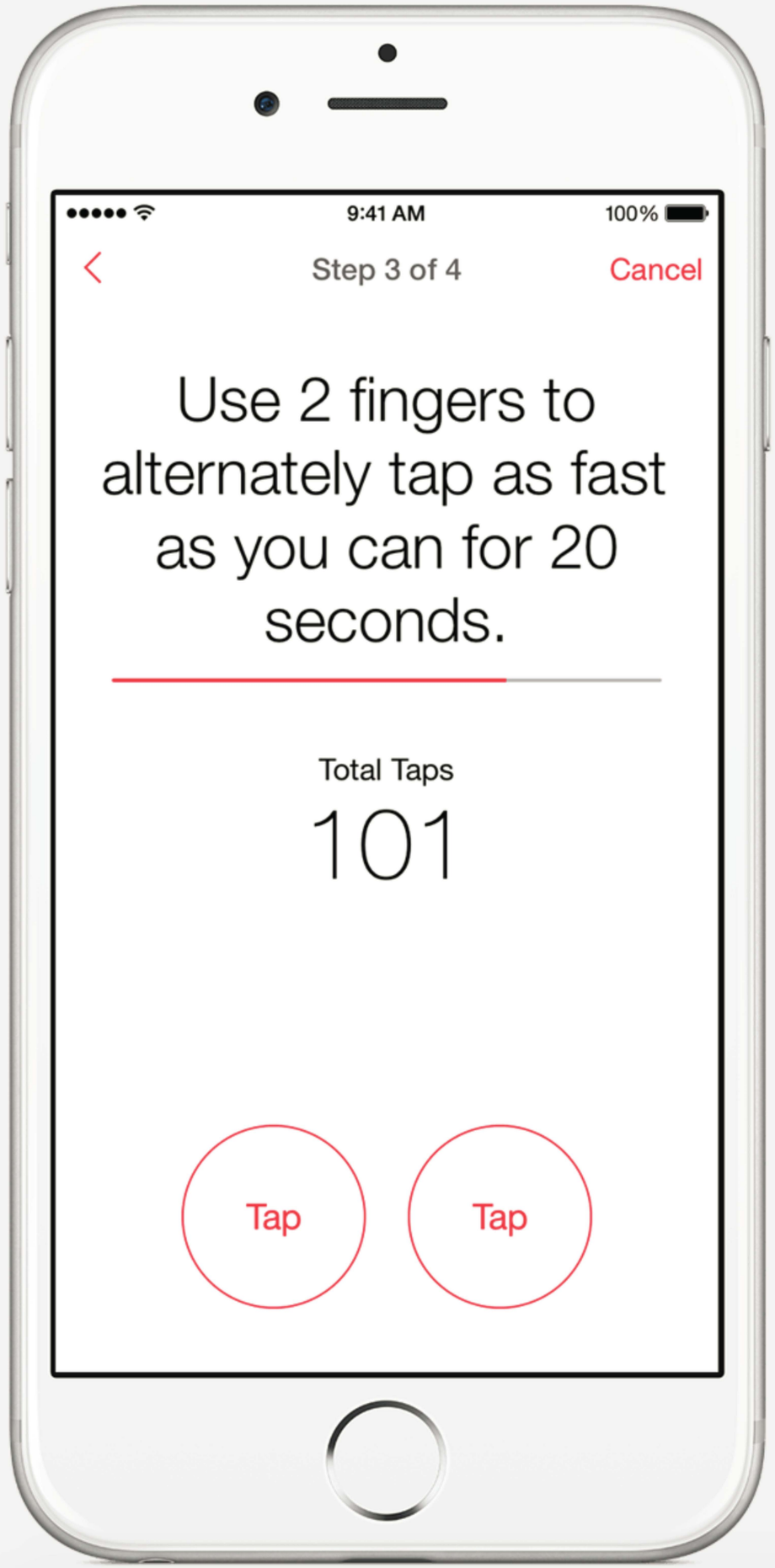
Home ▸ Data Descriptors ▸ Data Descriptor

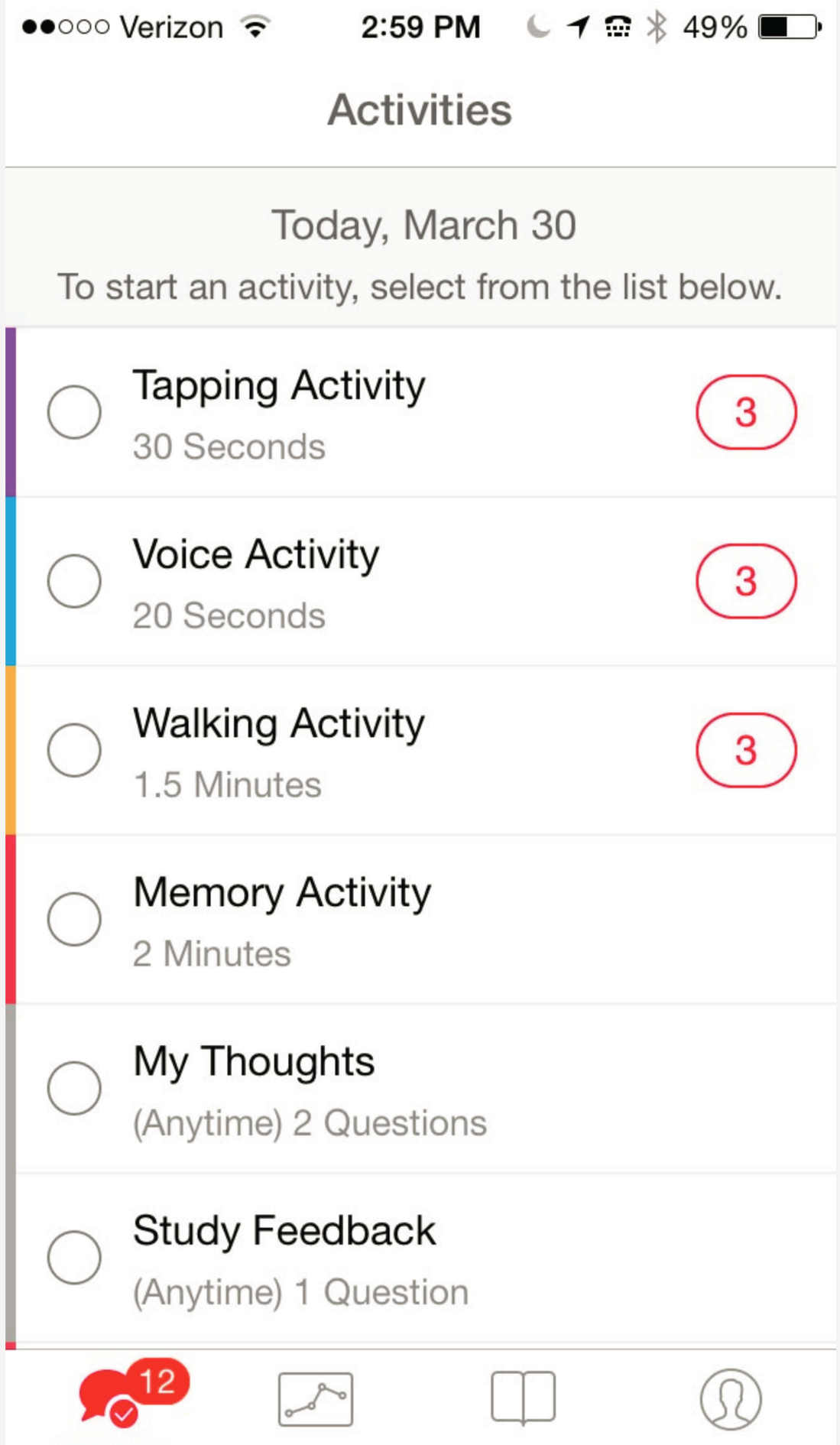
SCIENTIFIC DATA | DATA DESCRIPTOR OPEN

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

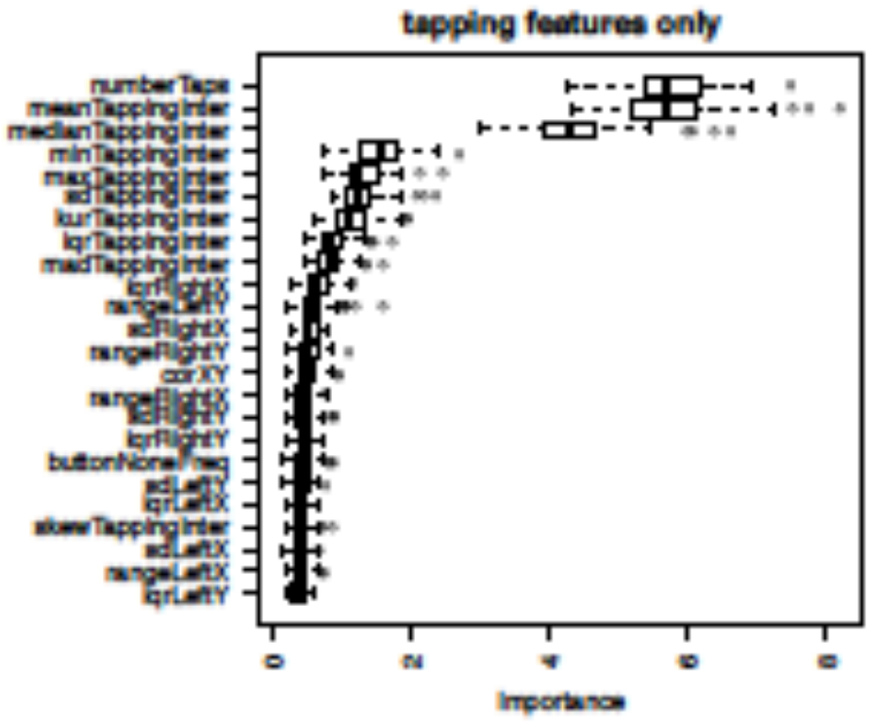

9:41 AM
100%
Step 3 of 4
Cancel
Use 2 fingers to alternately tap as fast as you can for 20 seconds.
Total Taps
101
Tap
Tap


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

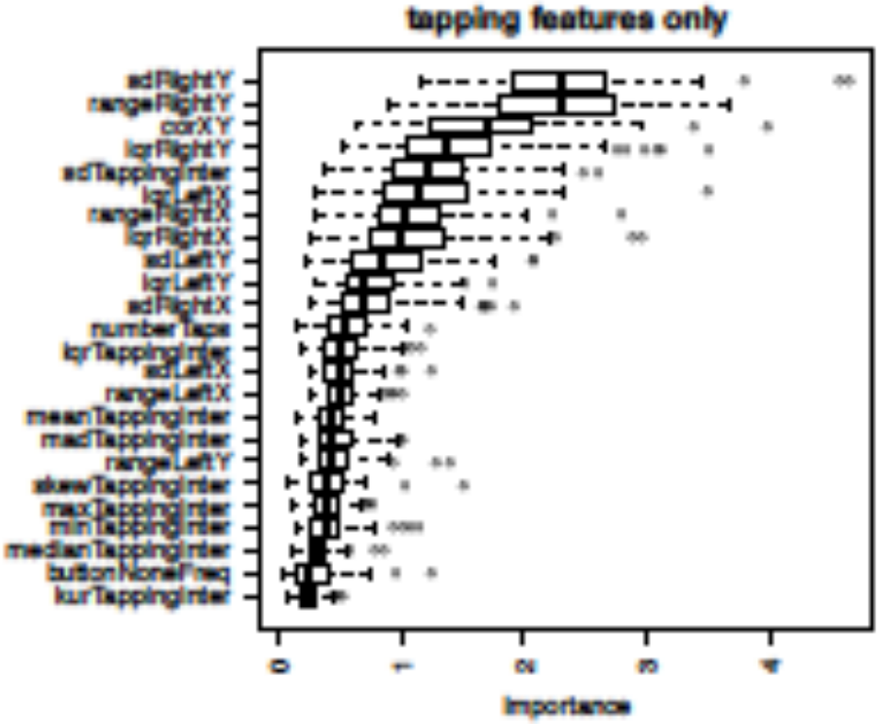
Traditional Measures	First-order Features
Number of Taps	Number of taps, Mean tapping interval, Median tapping interval, Minimum tapping interval, maximum tapping interval, Standard deviation of tapping interval, Kurtosis of tapping interval, Interquartile range of tapping interval, Interquartile range 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

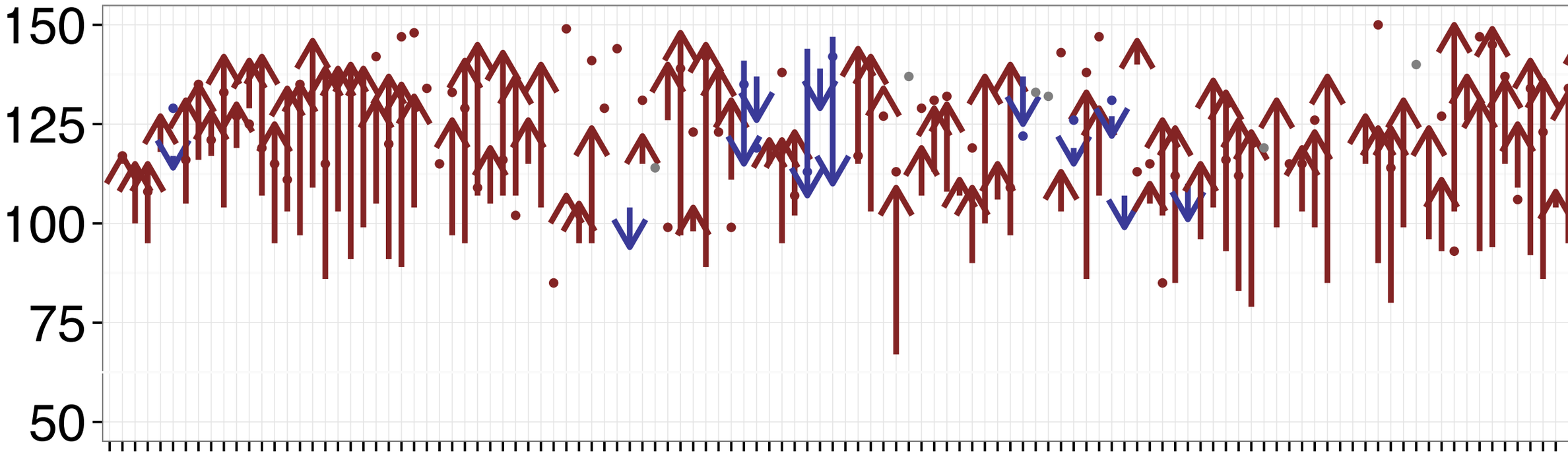
62 y old Man

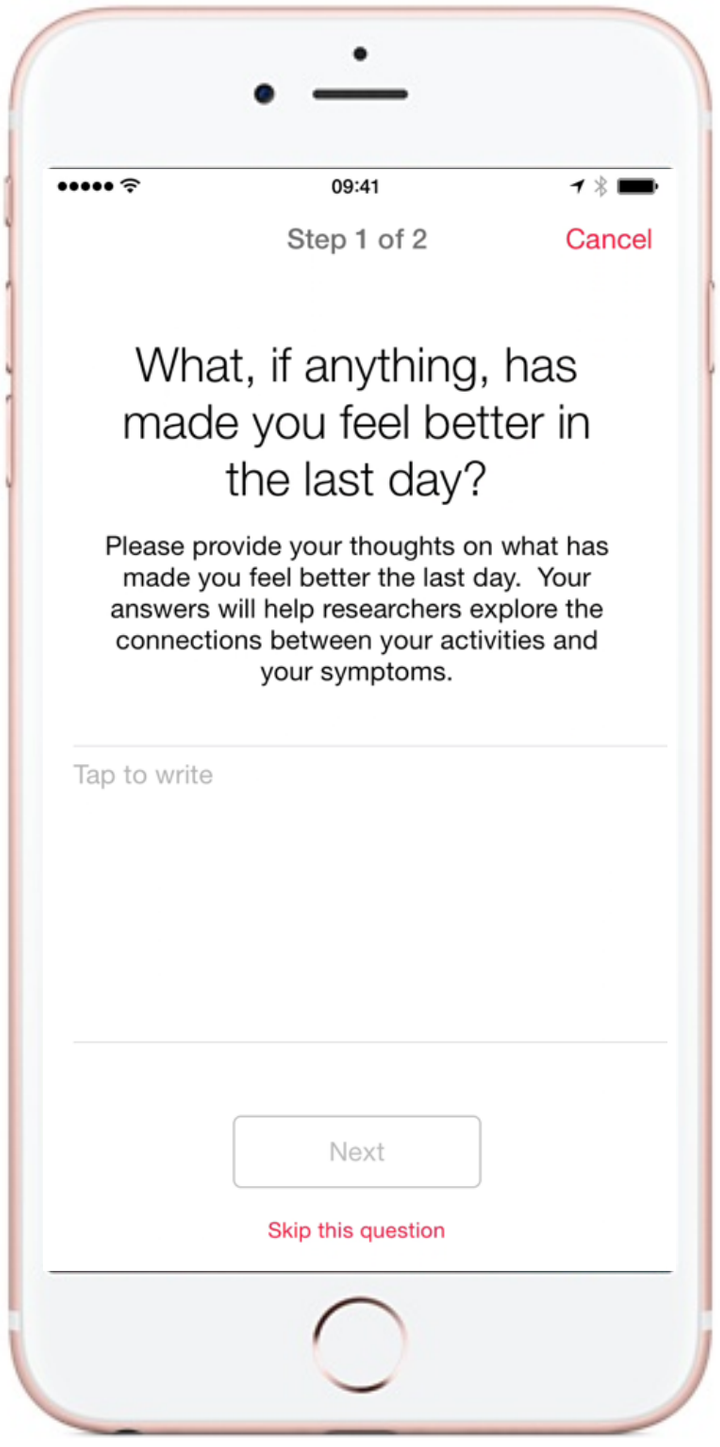


Standard Deviation R Y
Range Right Y
Correlation X Y

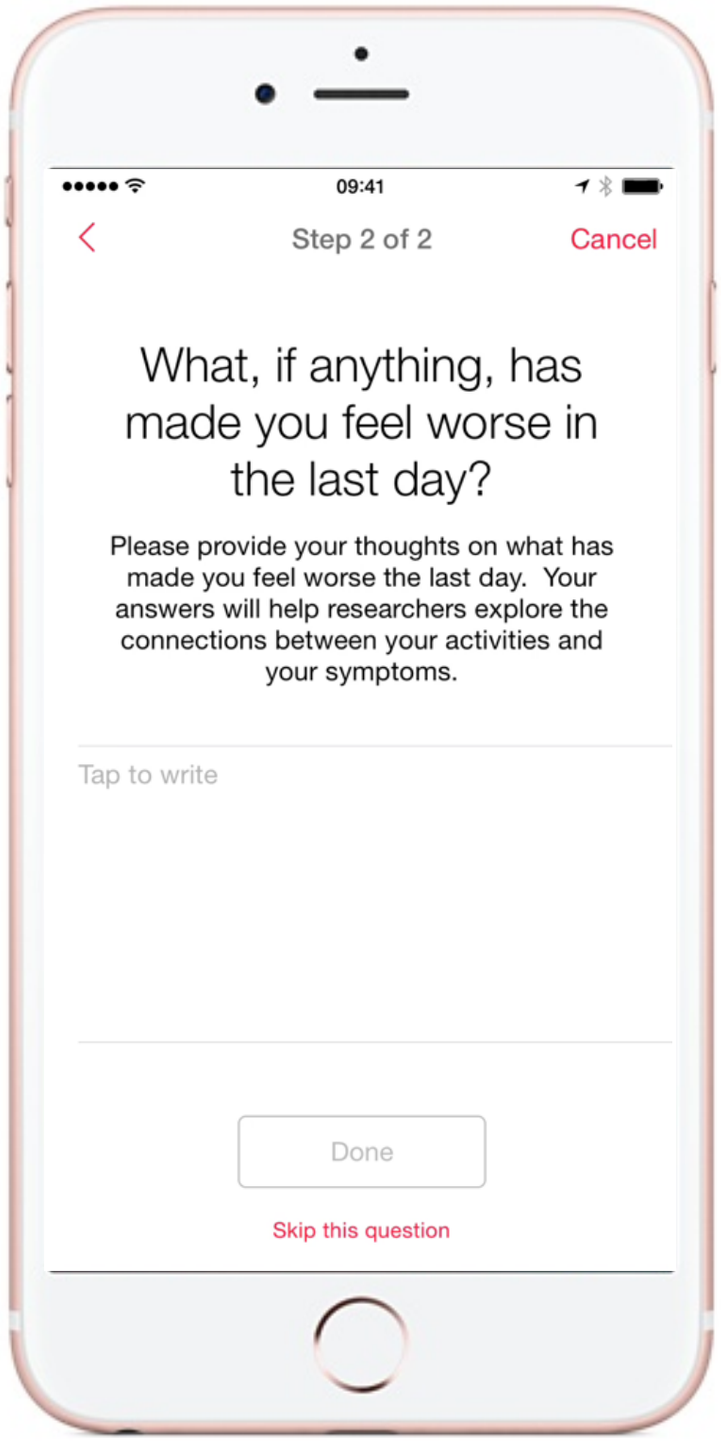
67 y old Woman

tapping number shows effects of medication and daily variation





sharing personal thoughts on day-to-day changes



“why isn’t this app as nice as spotify”

2.

issues and opportunities in e-consent

how do we avoid the consent traps of consumer technology?

comprehension
language
time
format

regulatory
liability

1. “technical debt” means traditional (non-mobile) consent has known problems, but hard to change.

2. signs of support for new methods of using technology as pedagogy in consent

This project was supported by grant number U18HS022789 from the Agency for Healthcare Research and Quality. The content is solely the responsibility of the authors and does not necessarily represent the official views of the Agency of Healthcare Research and Quality.

Additional funding came from the Robert Wood Johnson Foundation and the Helmsley Charitable Trust, and essential support from the Electronic Data Methods Forum at Academy Health.

pre-existing form, would probably first
, however slightly, in bodily structur
f so, whether the variations are transm
cordance with the laws which prevail wi
, are the variations the result, as far
ts us to judge, of the same general cau
e same general laws, as in the case of
by correlation, the inherited effe
subject to similar malconformati
ment, of reduplication of pa
of his anomalies reversion to
It might also

The biggest lie on the internet: "I have read and understood the terms of service"

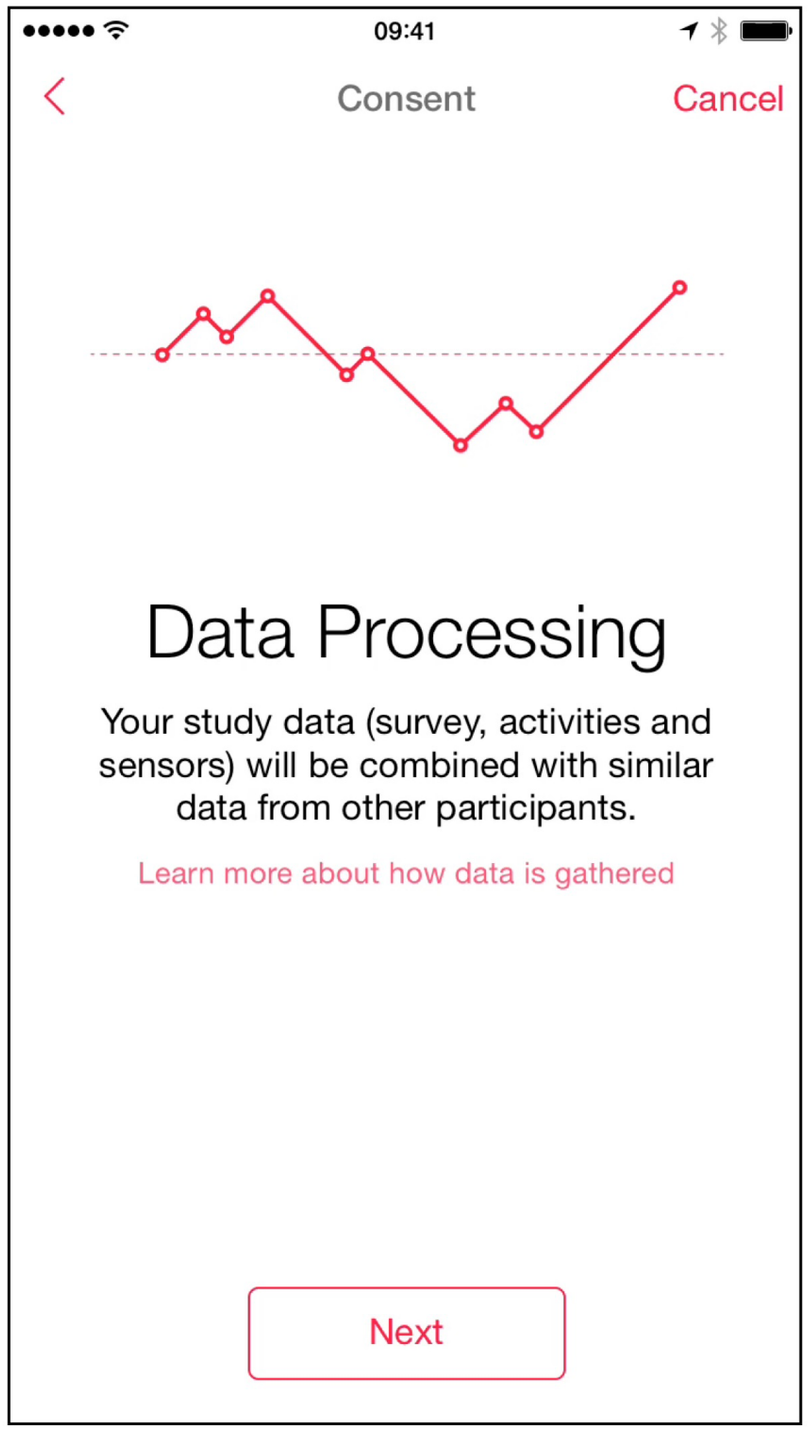
On July 7, two US academics published a paper entitled "The Biggest Lie on the Internet: "Ignoring the privacy policies and terms of service policies of social networking services" which details an experiment they carried out on 543 students, asking them to open

1. tiered information access by participants

2. “pictorial” dominant on first information tier

3. text dominant on second information tier

4. require perfect score on short assessment



“interface layer”

6:11 PM

Consent Cancel

Risk to Privacy

We will make every effort to protect your information, but total anonymity cannot be guaranteed.

Learn more

Next

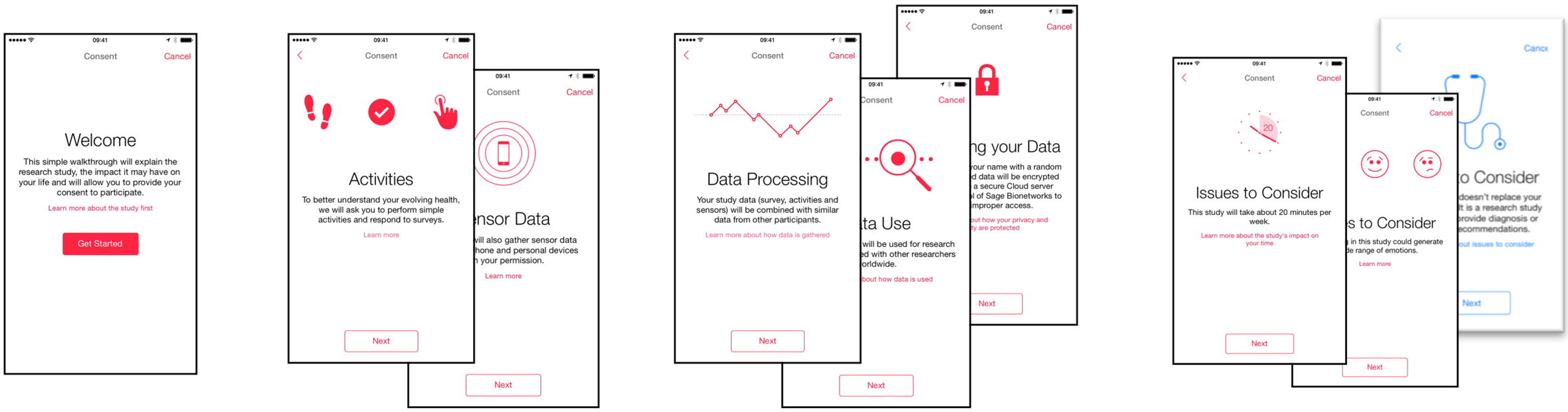
6:11 PM

Learn More Cancel

We take great care to protect your information, however there is a slight risk of loss of privacy. This is a low risk because we separate your personal information (information that can directly identify you, such as your name or phone number) from the research study data to respect your privacy. However, even with removal of this information, experts in re-identification may be able to reverse our processes and/or attempt to re-identify an individual given enough cross-reference information about him or her.

Accidental public disclosure may occur due to unintended data breaches including hacking or other activities outside of the procedures authorized by the study. In such a case, your data may be misused or used for unauthorized purposes.

study “narrative”

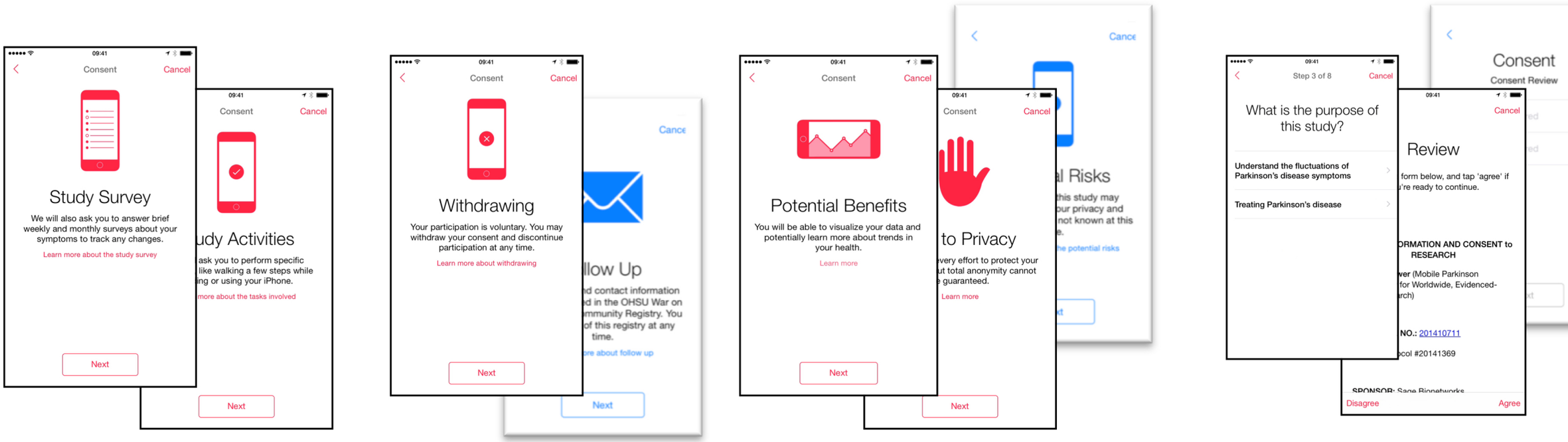


Welcome

The research

Your Data

impact on your life- Issues



What is involved

Your rights

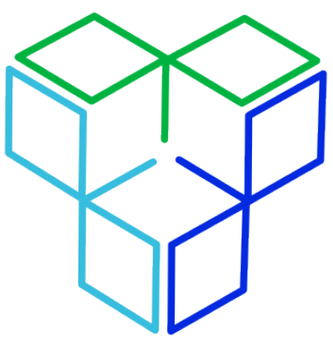
Potential risks and benefits

Comprehension- Review & Consent

externality:
lousy clinical protocols will be exposed as lousy clinical protocols.

3.

designing governance beyond consent



●●○○○ 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%

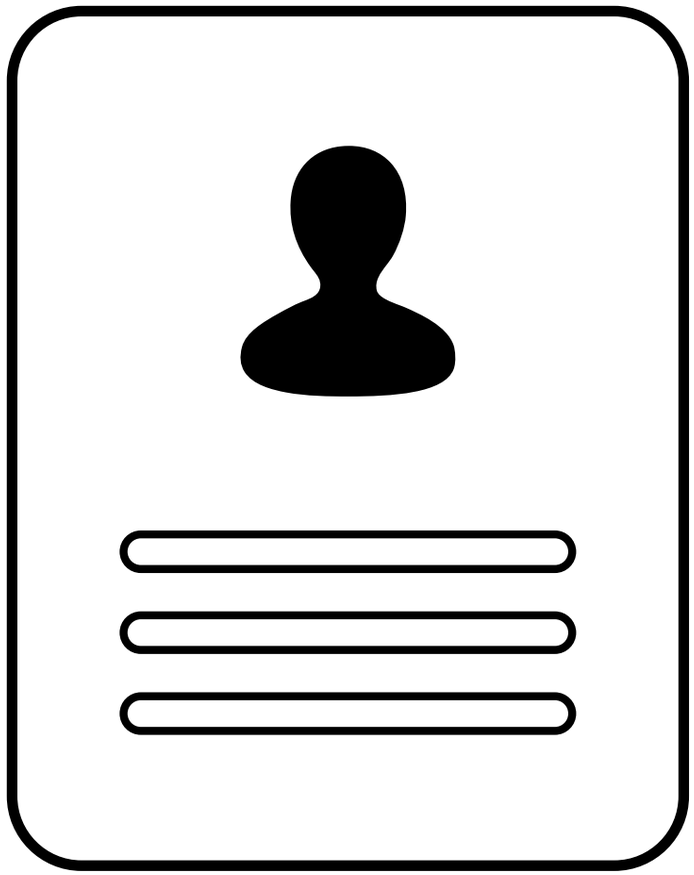
Cancel

Sharable Data

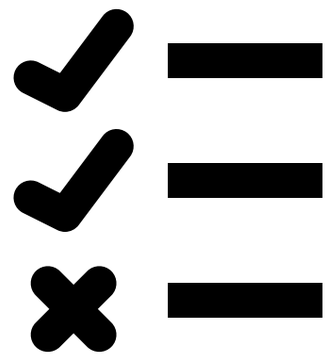
Only coded study data are sharable. Coded study data do not include your name or email address. A random code is used instead.

Learn more

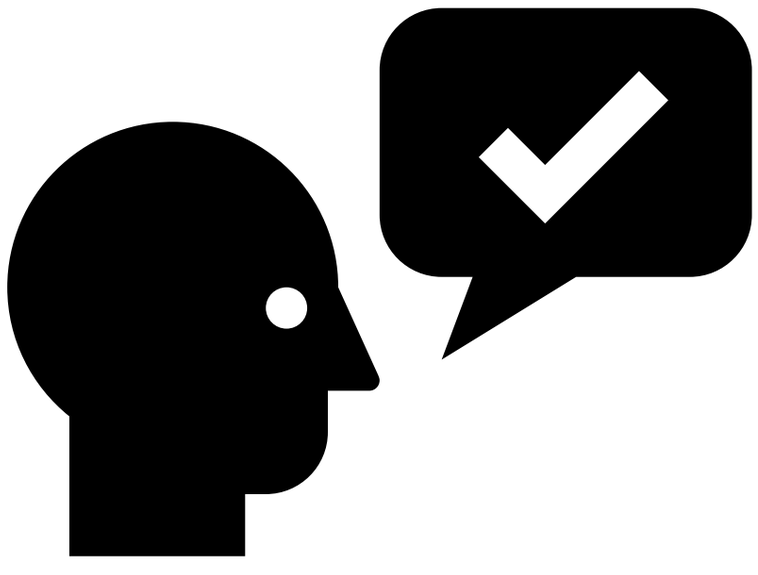
Next



identity

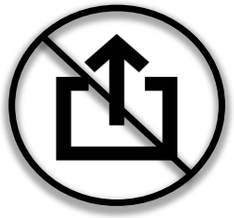
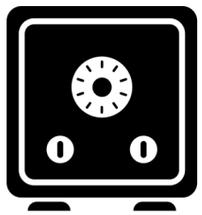


test



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

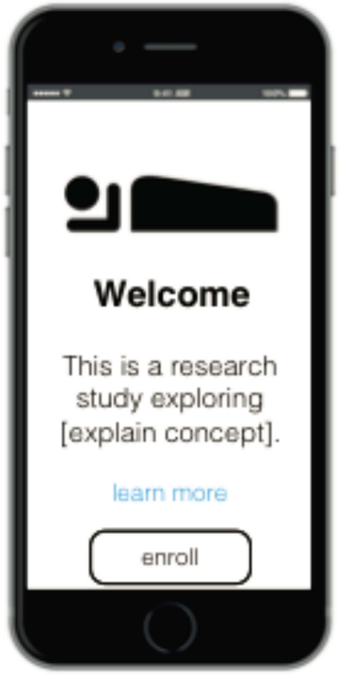
mPower six month data release

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

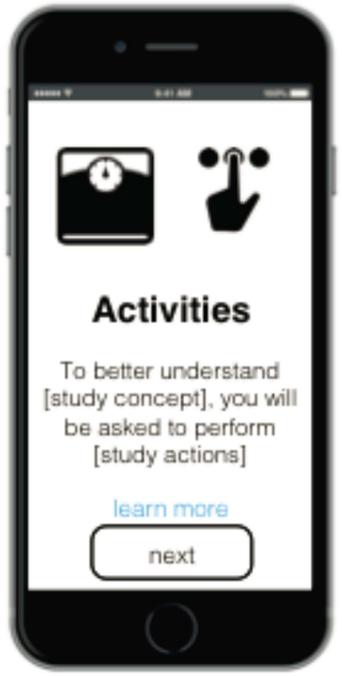
governance via sharing

iconographic representations of key concepts in informed consent



the icon should relate as directly as possible to the core concept of the study. in the example, we have included a sleeping person – appropriate for a sleep tracking study.

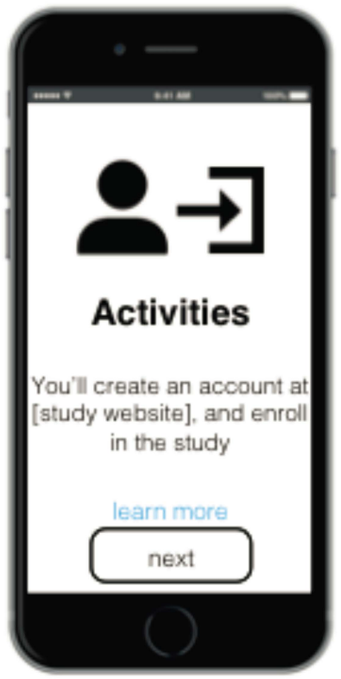
1

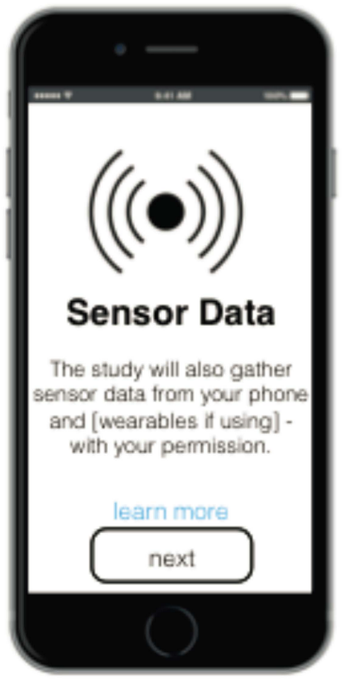


List the most common and important activities in plain language. Match with relevant icons – the connection of "on task" images with text is shown to increase attention and slow down the on-screen reading!

In this example, icons indicating self-tracking of weight and surveys are included.

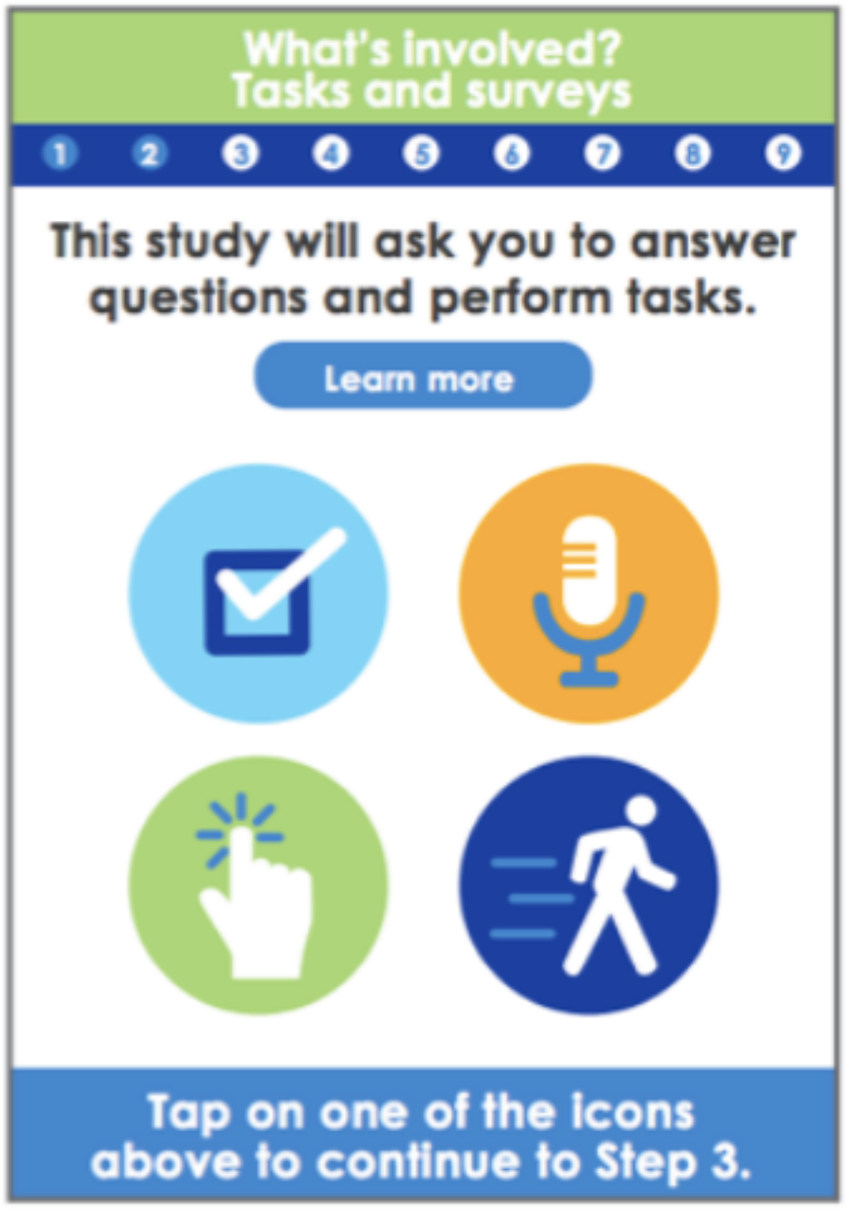
2





design layouts

The pages are organized in 6 distinct areas:



Title bar

Progress indicator

Text Information area

Learn more button
Opens to detailed text from the consent document.

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

Instruction area

web templates and assets

mPower: Mobile Parkinson Disease Study

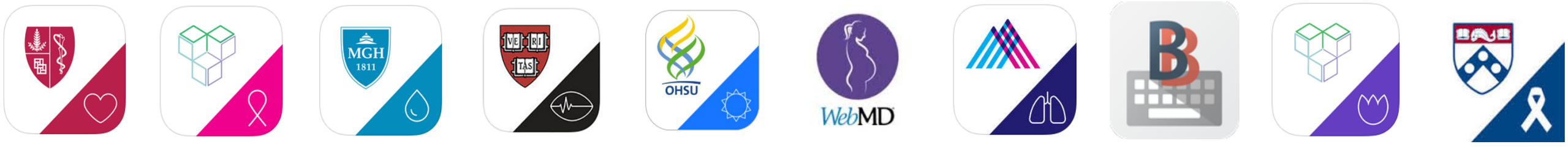
About this Study | How this Study Works | Who is Eligible to Participate | Who is Running this Study

About this Study

Become a research partner! How can we better manage the symptoms of Parkinson's disease (PD) together? Sage Bionetworks (nonprofit) is proposing a new approach to monitor health in PD using a mobile app. We want to understand why some people with PD have different symptoms than other people with PD, and why a person's symptoms and side effects can vary over time. The insights gained from this study may help develop ideas about how to manage these differences in symptoms.

Frequently Asked Questions

Learn More



100,000+ enrolled in Sage-supported studies since March 2015

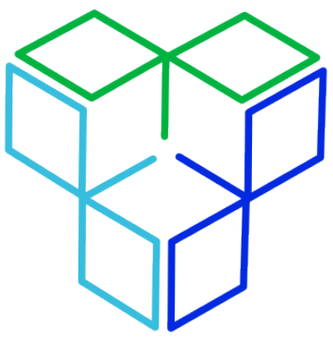
Phase I-III studies launched with partners

26 more known studies using methods

integrated into Apple ResearchKit

4.

where is this all going?



Atlanta

Boston

Chicago

Dallas

New York City

Washington, D.C.

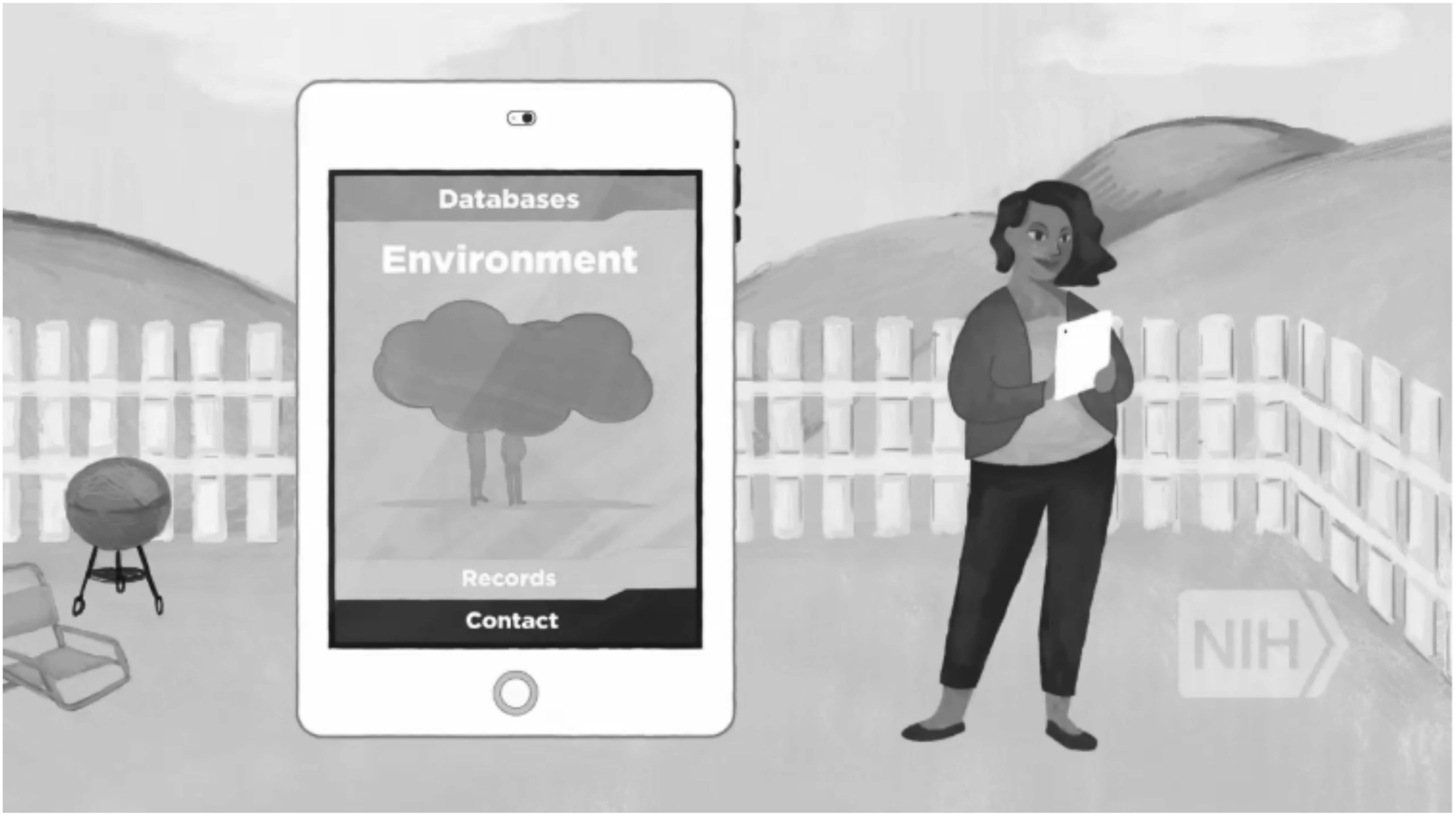
This is fundamentally a data problem. Algorithms learn by being fed certain images, often chosen by engineers, and the system builds a model of the world based on those images. If a system is trained on photos of people who are overwhelmingly white, it will have a harder time recognizing nonwhite faces.

Kate Crawford, AINow Founder

6:28
(off wrist)
verily
- and syncing (cont.)
verily Study Watch
Study Watch
Operator's manual
6:28
(off wrist)

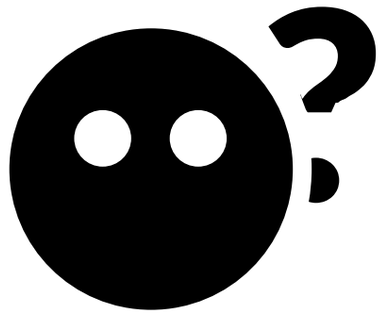
The future of health begins with All of Us

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.


Databases
Environment
Records
Contact
NIH

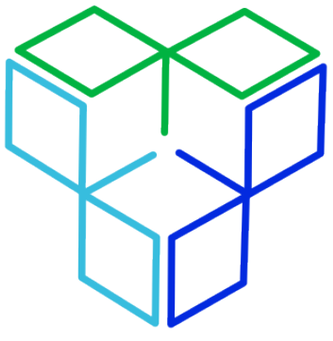
Identifiability

Knowable harms



Unknown unknowns

DNA sequencing and results return are different from sensors and surveys - have to teach and assess higher risk, uncertainty, unknowables…

please @ me

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