

transforming clinical study through
participant-centric mobile research

Current at Sage

ResearchKit.

Sage Bionetworks, Together with Oregon Health and Science University, Launches Mole Mapper, an iPhone-app Research Study to Better Understand Melanoma

[Mole Mapper](#), available for [download in the App Store](#), joins two iPhone app studies: [Parkinson mPower](#) and [Share the Journey](#) (focused on breast cancer survivors) launched earlier this year on Apple's ResearchKit platform. [Learn](#)



White House Celebrates 5th Anniversary of Challenge.gov with More Than 20 New Prizes

Highlighted with the White House announcement: The Foundation for the National Institutes of Health, the National Cancer Institute and **Sage Bionetworks**, with support from the Laura and John Arnold Foundation.

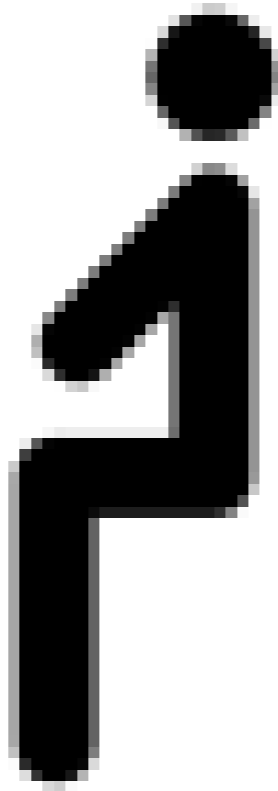


With the opening of the IBM Watson Health headquarters, IBM and Sage announce an Open Biomedical Research Platform,

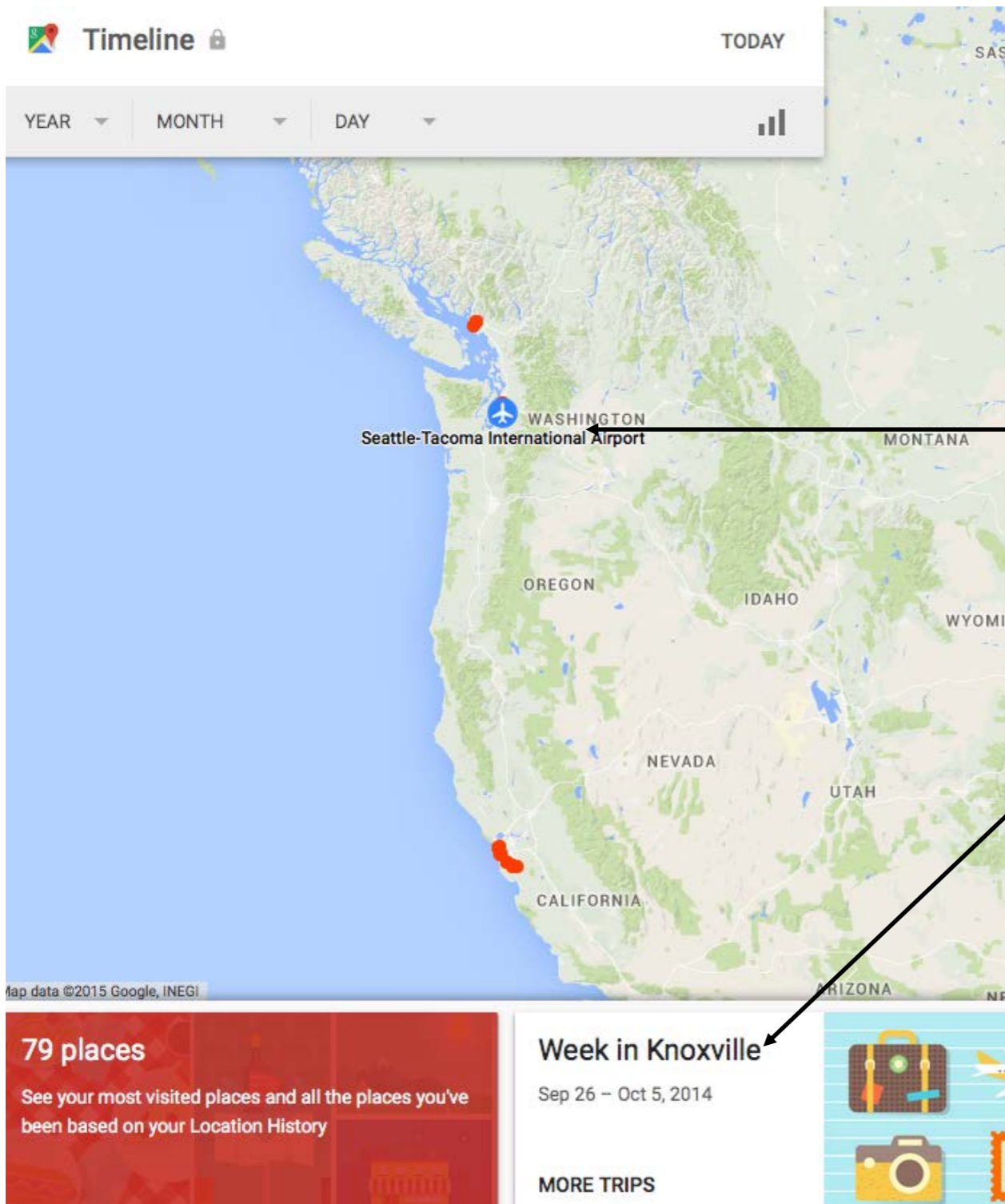
comprising Sage's Bridge Server and Synapse technologies powered by the IBM Watson Health Cloud and associated analytics. The platform will

1.

mobile brings prediction, massive
sample sizes, machine learning.



the old promise is: you're my subject.
trust me to make things better.



where i've been,
where i'm going

To predict whether or not we'll click on ads, Facebook / Amazon / Google have **longitudinal data on individuals**.

Finalize the details of your Targeting Groups

Each Targeting Group selected will be created as a separate Ad Set on Facebook.

Ad Set Creation Queue

These are your generated Ad Sets. Configure each Ad Set's settings and set a default bid for all Ads within each set. Bid values for individual Ads can be overwritten from the Ad upload step.

Ad Set Name	Delivery Pacing	Budget	Flight Dates	Bid	Initial Status	Actions
New Zealand-all-genders Targeting Group Name: New Zealand-all-genders	<input type="radio"/> Standard <input checked="" type="radio"/> Day Parting 12AM 1 2 3 4 5 6 7 8 9 10 11 12 1 2 3 4 5 6 7 8 9 10 11 M T W T F S S [Dayparting grid with green cells]	<input checked="" type="radio"/> Lifetime <input type="radio"/> Daily \$ 100.00	Apr 22 '15 at 2:18 PM until Apr 23 '15 at 12:00 AM 0.4 days total	oCPM to Actions \$ 2.00 Suggested: \$ 1.86	<input type="radio"/> Paused <input checked="" type="radio"/> Active	[Icons]
New Zealand-all-genders Targeting Group Name: New Zealand-all-genders	<input type="radio"/> Standard <input checked="" type="radio"/> Day Parting 12AM 1 2 3 4 5 6 7 8 9 10 11 12 1 2 3 4 5 6 7 8 9 10 11 M T W T F S S [Dayparting grid with green cells]	<input checked="" type="radio"/> Lifetime <input type="radio"/> Daily \$ 100.00	Apr 22 '15 at 2:18 PM until Apr 23 '15 at 12:00 AM 0.4 days total	CPC \$ 1.00 Suggested: \$ 0.75	<input type="radio"/> Paused <input checked="" type="radio"/> Active	[Icons]

Create 2 Ad Sets

Go Back

To predict whether or not we'll click on ads, Facebook / Amazon / Google use **sample sizes in the hundreds of thousands.**

↑ > Current Issue > vol. 111 no. 24 > Adam D. I. Kramer, 8788–8790, doi: 10.1073/pnas.1320040111



Experimental evidence of massive-scale emotional contagion through social networks

Adam D. I. Kramer^{a,1}, Jamie E. Guillory^{b,2}, and Jeffrey T. Hancock^{b,c}

Author Affiliations

Edited by Susan T. Fiske, Princeton University, Princeton, NJ, and approved March 25, 2014 (received for review October 23, 2013)

A correction has been published

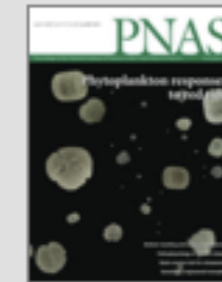
A correction has been published

Abstract Full Text Authors & Info Figures Metrics Related Content PDF

Significance

We show, via a massive ($N = 689,003$) experiment on Facebook, that emotional states can be transferred to others via emotional contagion, leading people to experience the same emotions without

This Issue



June 17, 2014
vol. 111 no. 24
Masthead (PDF)
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NEXT ARTICLE ▶

Don't Miss

Customize your free PNAS alerts to receive a notification as new content becomes available.

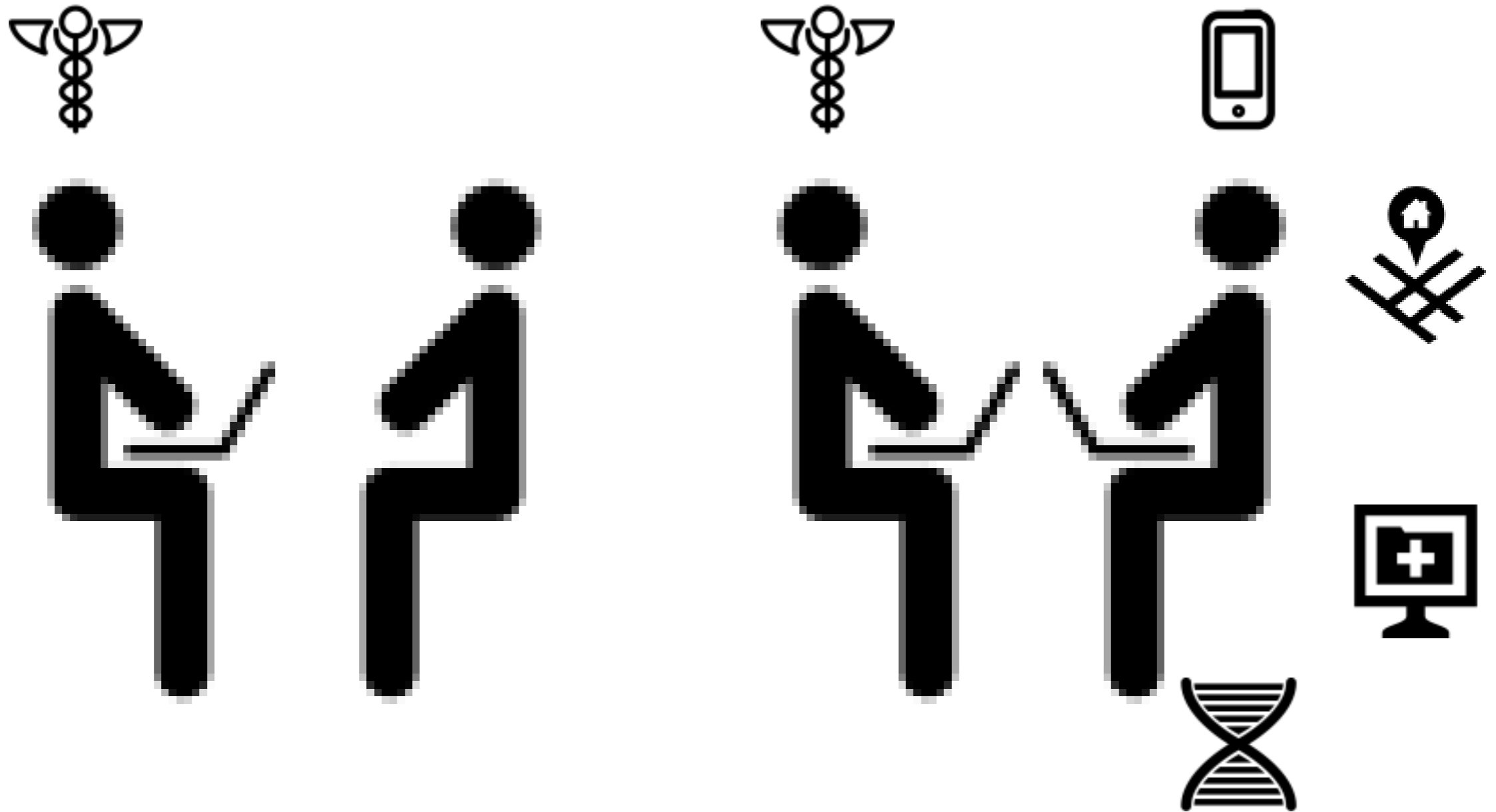
Navigate This Article

▲ Top

○ Abstract

○ Acknowledgments

n=689,003



this data isn't coming in via the old promises and methods.



the new promise is: you're **my partner now**, and we need to work **together**.



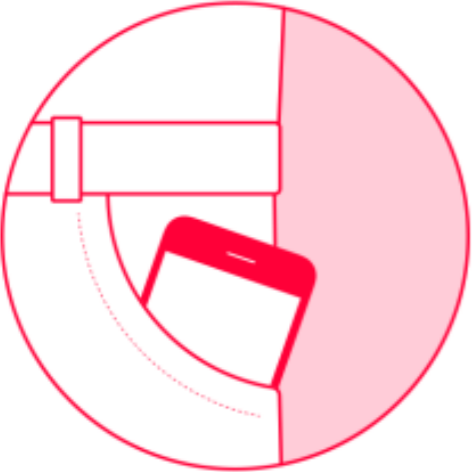
... every six months, the team will conduct p

6:26 PM

Step 1 of 6 Cancel

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.

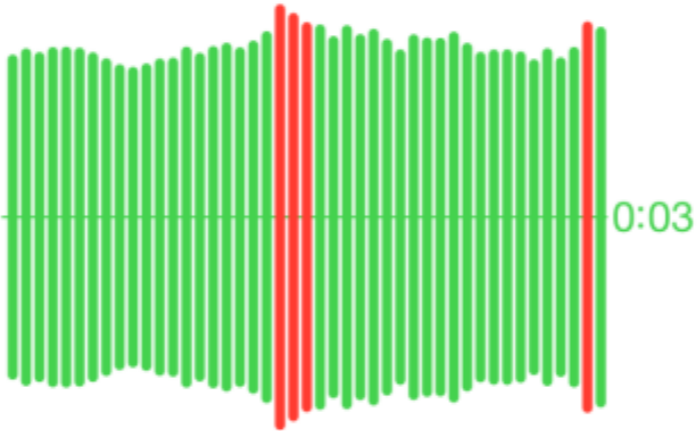


Get Started

6:25 PM

Step 5 of 6 Cancel

Say "Aaaaah" into the microphone for as long as you can.



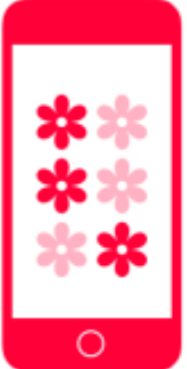
0:03

6:24 PM

Step 1 of 4 Cancel

Spatial Memory Test

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



Next

includes timing of medications

Tapping Interval Test

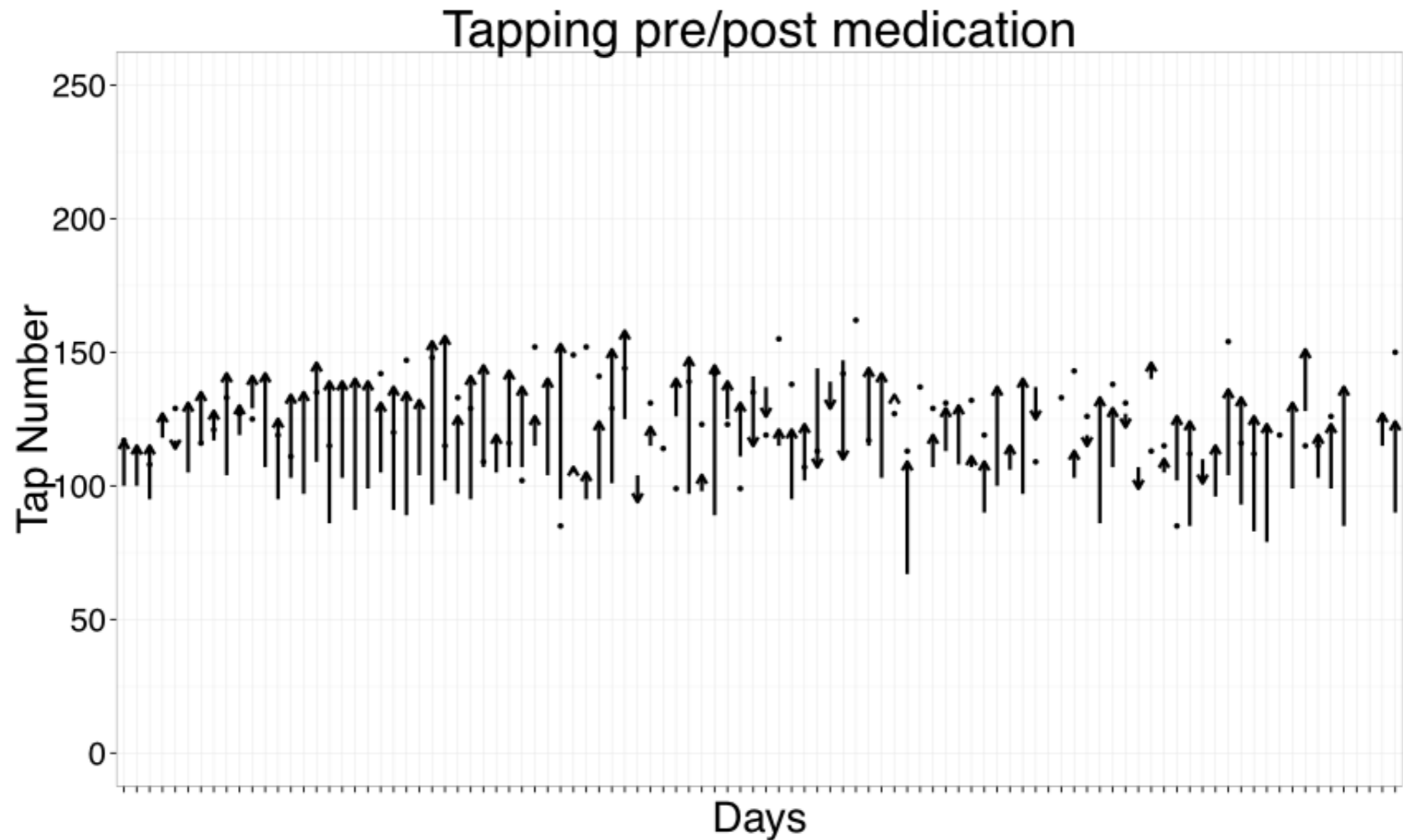
Rest your phone on a flat surface. Then use two fingers on the same hand to alternately tap the buttons that appear. Keep tapping for 20 seconds and time your taps to be as consistent as possible.

Tap Get Started to begin the test.



includes timing of medications

individual progression



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 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

- 5,192 unique participants provided 17,076 responses to questions about what made them feel better or worse on that day

Examples of Better:

"I went to visit with family that made me feel better"
"Sinemet and lying down for an hour in the afternoon."
"Laying down"
"The sun starting to come out in the warmth of the day because were entering spring"
"I got some really good news about a stray cat of the nursing back to health."
"Meetings"
"Computer games"
"Completing a list of tasks for daily activities"
"Looking for furniture for my new house"
"Practicing Zen Meditation!"

Examples of Worse:

"Walking"
"Not getting a good nights sleep the night before"
"I don't think anyone in my family really understands what Parkinson's disease is and how it is impacting my life and my work."
"Worrying that I not getting things done around the house"
"Having a glass of wine"
"Nothing"
"Sadness regarding race relations in America!"
"Getting comfortable sleeping. Keep moving my sleeping position which leads to restless night."

“loads and reliefs” affect the efficacy of medication

recombining studies...which means

radical honesty
> radical restrictions

informed consent is the key.

2.

how can we increase
informedness in mobile or
digital consent?



messages and anyone in a message conversation can reply to it.

How we use the information we receive

We use the information we receive about you in connection with the services and features we provide to you and other users like your friends, our partners, the advertisers that purchase ads on the site, and the developers that build the games, applications, and websites you use. For example, in addition to helping people see and find things that you do and share, we may use the information we receive about you:

- as part of our efforts to keep Facebook products, services and integrations safe and secure;
- to protect Facebook's or others' rights or property;
- to provide you with location features and services, like telling you and your friends when something is going on nearby;
- to measure or understand the effectiveness of ads you and others see, including to deliver relevant ads to you;
- to make suggestions to you and other users on Facebook, such as: suggesting that your friend use our contact importer because you found friends using it, suggesting that another user add you as a friend because the user imported the same email address as you did, or suggesting that your friend tag you in a picture they have uploaded with you in it; and



research

- for internal operations, including troubleshooting, data analysis, testing, research and service improvement.

exists today, but it also allows us to provide you with innovative features and services we develop in the future that use the information we receive about you in new ways.

While you are allowing us to use the information we receive about you, you always own all of your information. Your trust is important to us, which is why we don't share information we receive about you with others unless we have:

- received your permission;
- given you notice, such as by telling you about it in this policy; or
- removed your name and any other personally identifying information from it.

Example: cluster DNA



Long term, high value,
frequent buyers
\$99 average order
\$2,261 total revenues
24 days between orders
24 total orders
57 total items
\$76 first order revenues
1.7 products in first order
6% of orders on clearance
+10 more



High value, fewer orders,
big spend on 1st order
\$124 average order
\$595 total revenues
67 days between orders
5 total orders
14 total items
\$164 first order revenues
3.3 products in first order
3% of orders on clearance
+10 more

AGILONE

what happens if we import toxic ethics
from tech to health?

El que suscribe, *Nicanor*

Fernandez

mayor de veinte y cinco años de

edad, natural de

Citoviro

provincia de *Oreense*

hijo de

José Fernandez

y de *Dominga Estvez*

hace constar por la presente que,

y ejerciendo su propia y libérrima voluntad, consiente en someters

experimentos que con el objeto de determinar las vías de propagaci

tiere amarilla, haga en su persona la Comision que para ese efecto

brado, el Secretario de la Guerra de los Estados Unidos: que dé su

imiento para que se lleven a cabo dichos experimentos, por las raz

con las condiciones que abajo se expresan.

El infrascrito comprende perfectamente bien que en el caso de

ollarse en él la fiebre amarilla, ha de peligrar su vida hasta cie

pero siendole completamente imposible evitar el contagio durante

comprehension

language

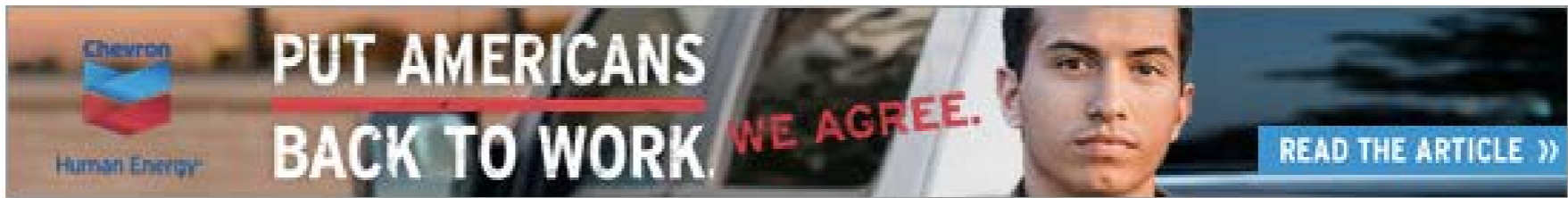
time

format

regulatory

liability

pre-existing form, would probably first
be, however slightly, in bodily structure
if so, whether the variations are transe
accordance with the laws which prevail wit
, are the variations the result, as far
lets us to judge, of the same general caus
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 naturally be



Ad

Speaking Of Science

Londoners accidentally pay for free Wi-Fi with a firstborn, because no one reads anymore



By **Rachel Feltman** September 29 Follow @rachelfeltma



Advertisement

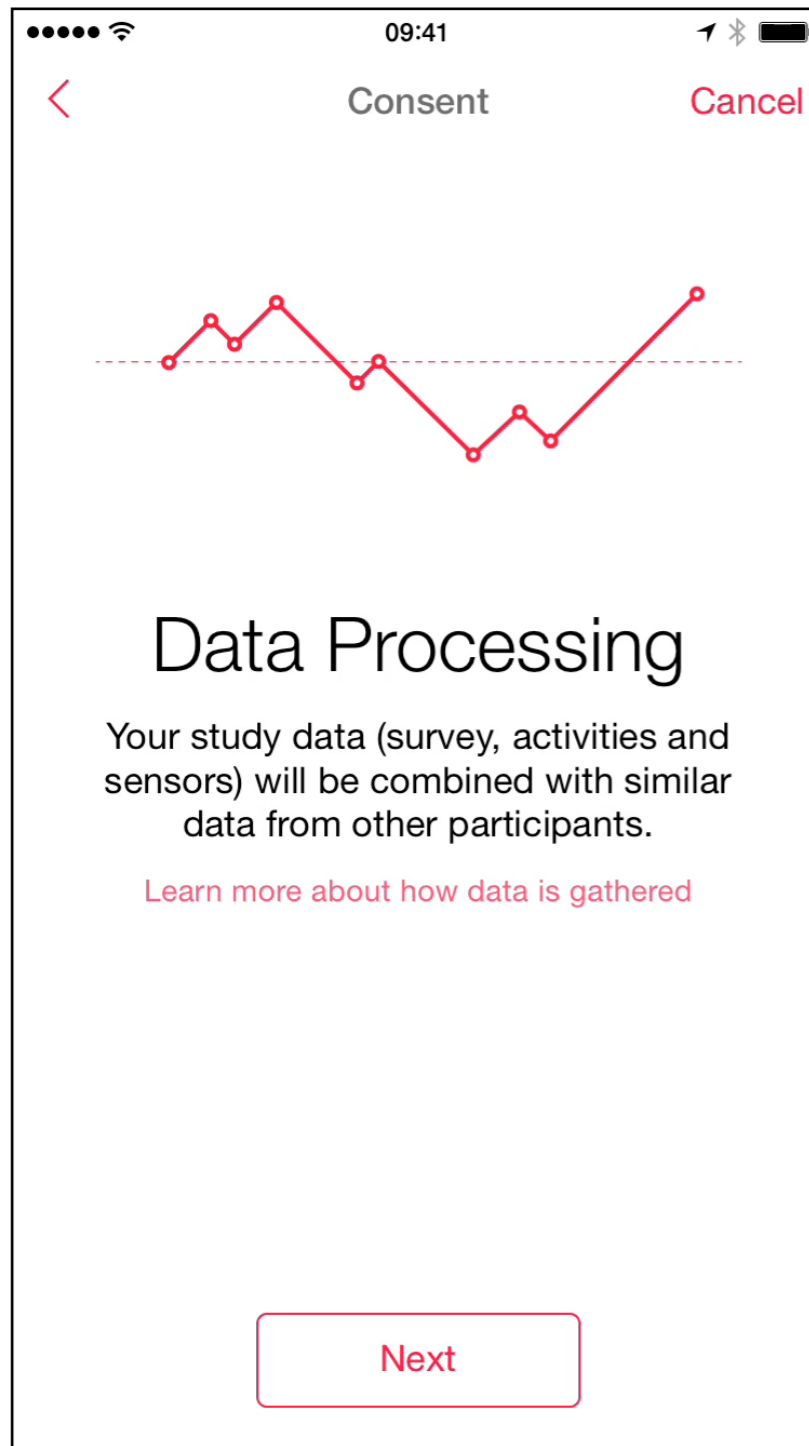
JOB ARTICLES

- 
 Survey: US companies added 208,000 jobs last month
[Read more](#) December 3, 2014
- 
 Stocks slip on ECB stimulus speculation
[Read more](#) December 4, 2014
- 
 US stocks extend record run ahead of jobs report
[Read more](#) December 3, 2014

SEE OUR PERSPECTIVE >>



screens are organized in consistent areas



Navigation

Visual Information area

Graphics demonstrate and reinforce the information provided in text.

Main Concept

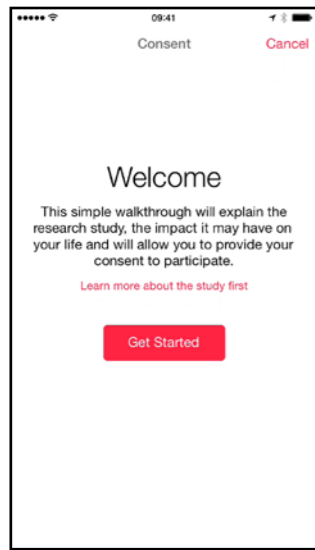
Text Information area

Learn more links

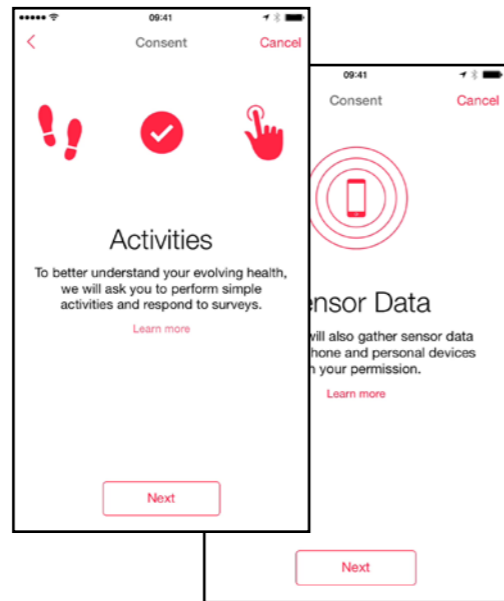
Opens to detailed text from the consent document.

Instruction area

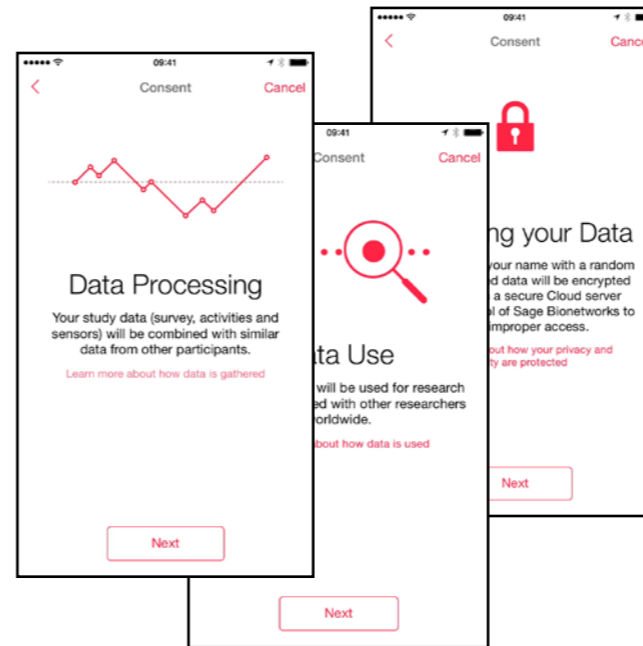
tell the “story of the study”



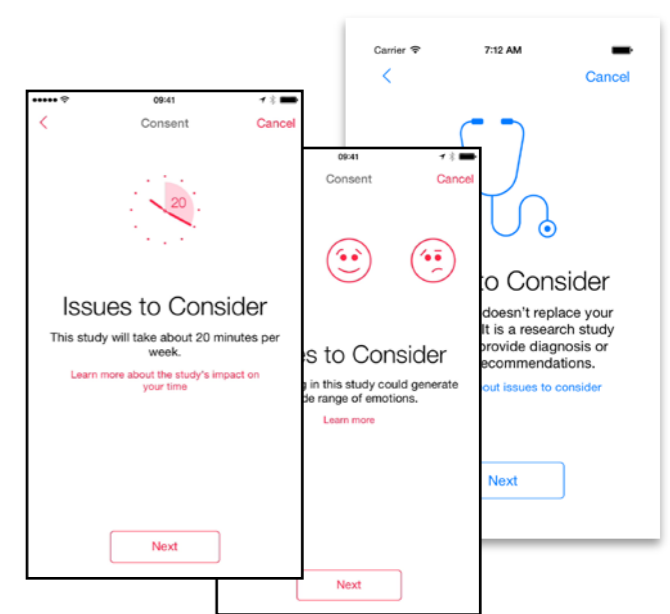
Welcome



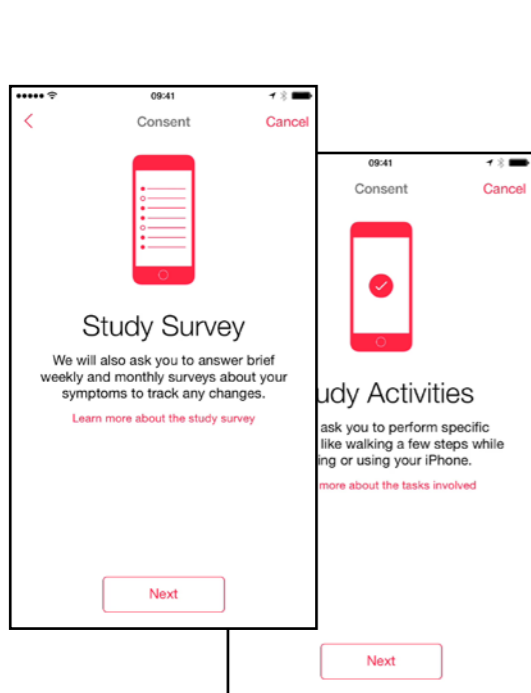
The research



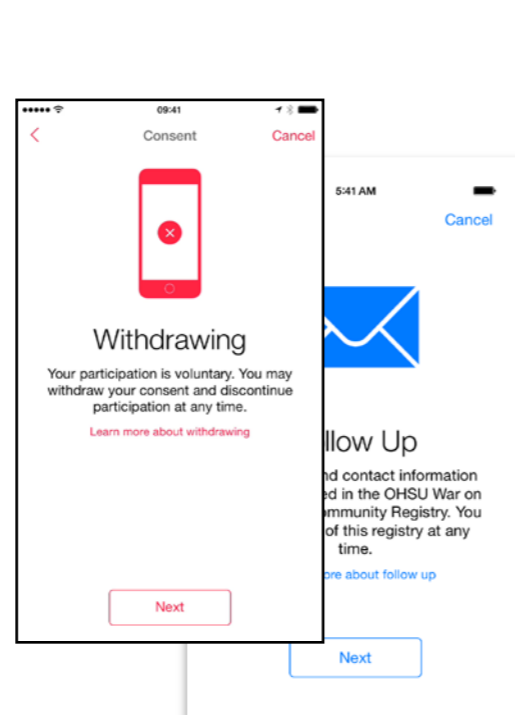
Your Data



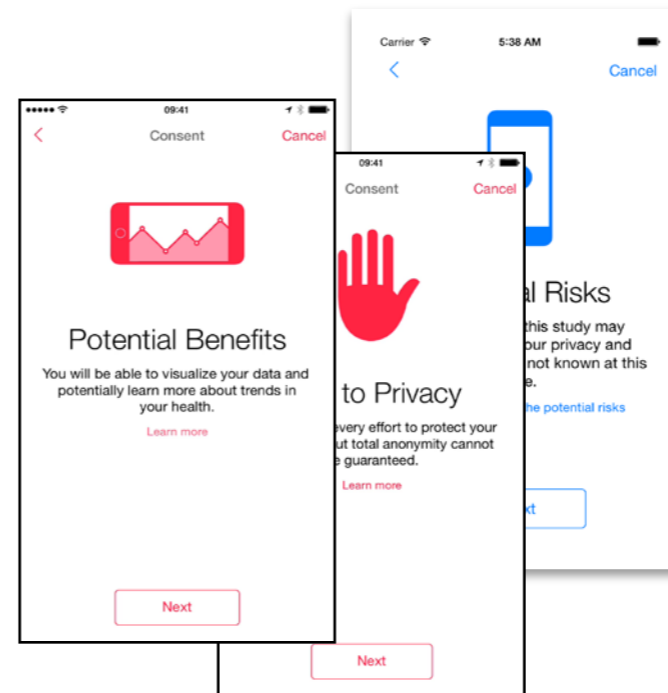
impact on your life - Issues



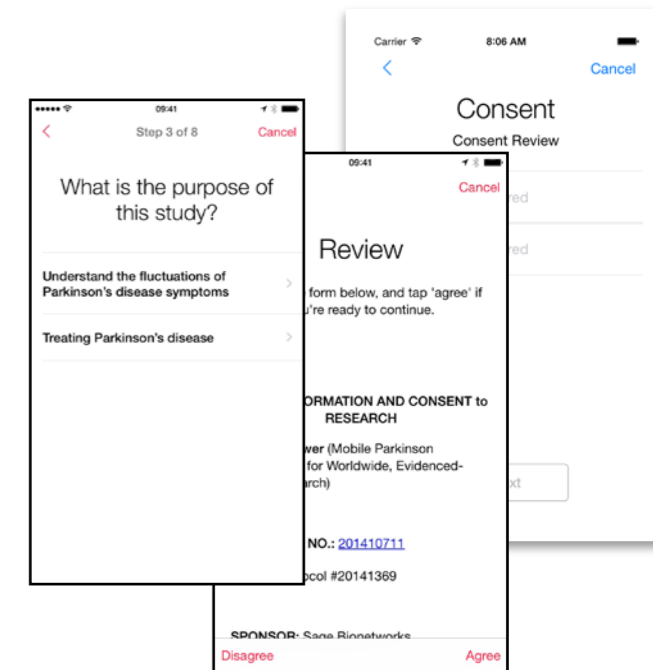
What is involved



Your rights



Potential risks and benefits



Comprehension- Review & Consent



Consent

Cancel



Sensor Data

This study will also gather sensor data from your iPhone and personal devices with your permission.

[Learn more](#)

Next

[Learn More](#)

Cancel

You have the option to contribute activity data collected through:

- The sensors on your iPhone or any wearable activity device (like a Fitbit or Jawbone)
- Other applications and data available through Healthkit.

You can choose not to provide this data and still participate in the study.

We will NOT access your personal contacts, other applications, personal photos, text or email messages.



Consent

Cancel



Data Processing

Your study data (survey, activities and sensors) will be combined with similar data from other participants.

[Learn more about how data is gathered](#)

Next

Learn More

Cancel

We will electronically process your data.

We will separate your account information (name, email, contact information, etc.) from your study data (your responses to surveys and the measurements from the phone itself when you perform activities).

We will combine your coded study data (without your name) with those of other study participants to be analyzed.

WE WILL NEVER SELL, RENT OR LEASE YOUR CONTACT INFORMATION.



Consent

Cancel



Issues to Consider

Participating in this study could generate a wide range of emotions.

[Learn more](#)

Next

[Learn More](#)

Cancel

Participating in this study may change how you feel. You may feel tired, sad, energized or happy.

Participation in this study may involve risks that are not known at this time. You will be told about any new information that might change your decision to be in this study.



Consent

Cancel



Risk to Privacy

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

[Learn more](#)

Next

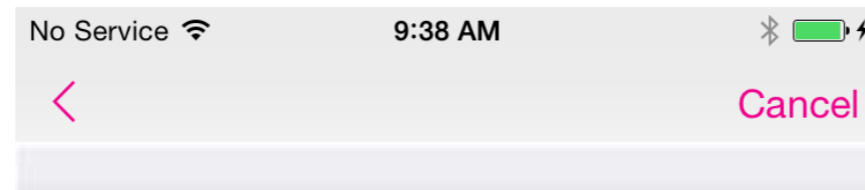
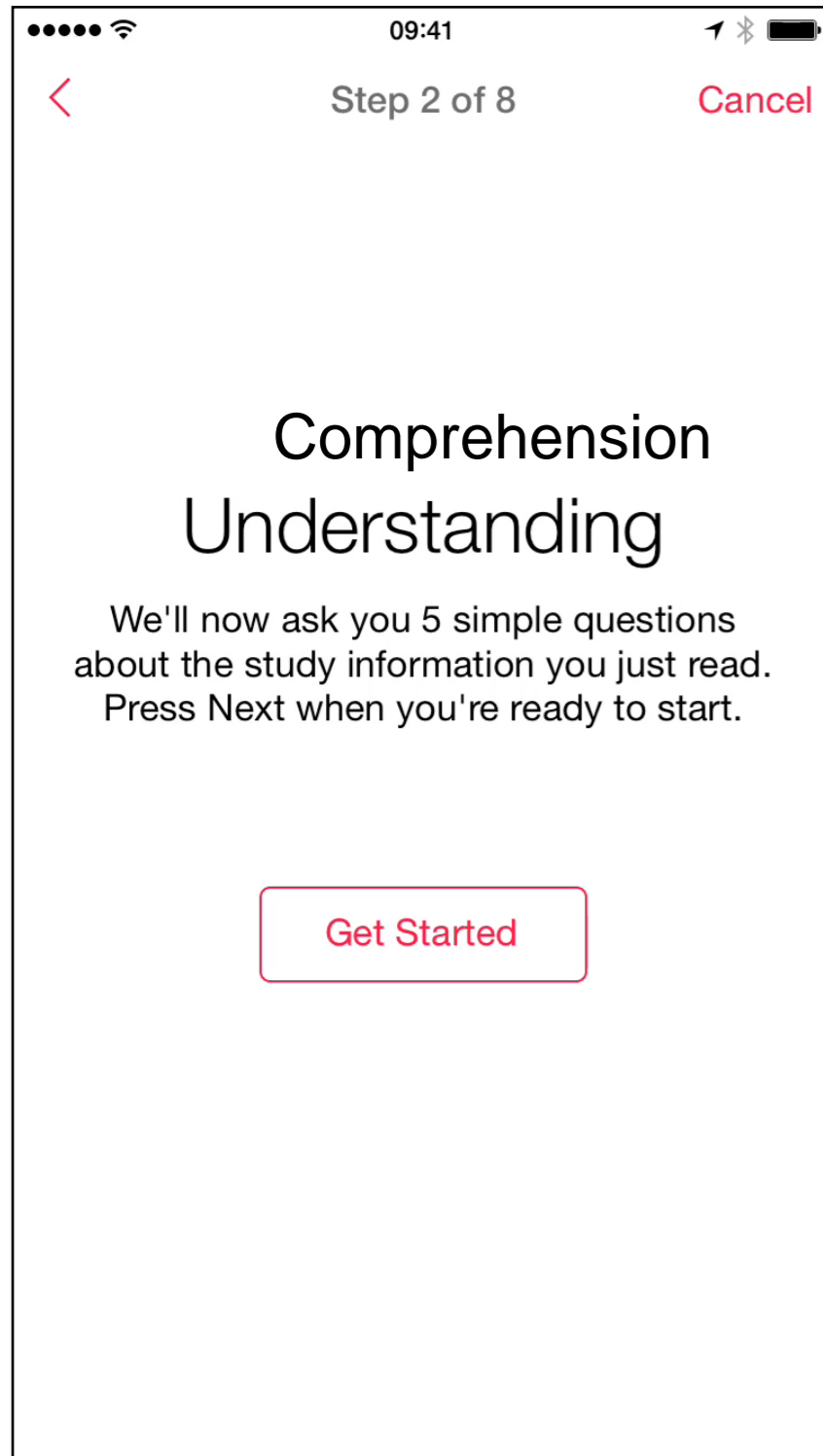
[Learn More](#)

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.

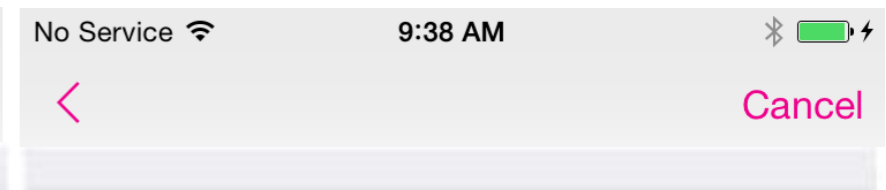
comprehension assessment




Great Job!

You answered all of the questions correctly.
Tap Next to continue.

Next

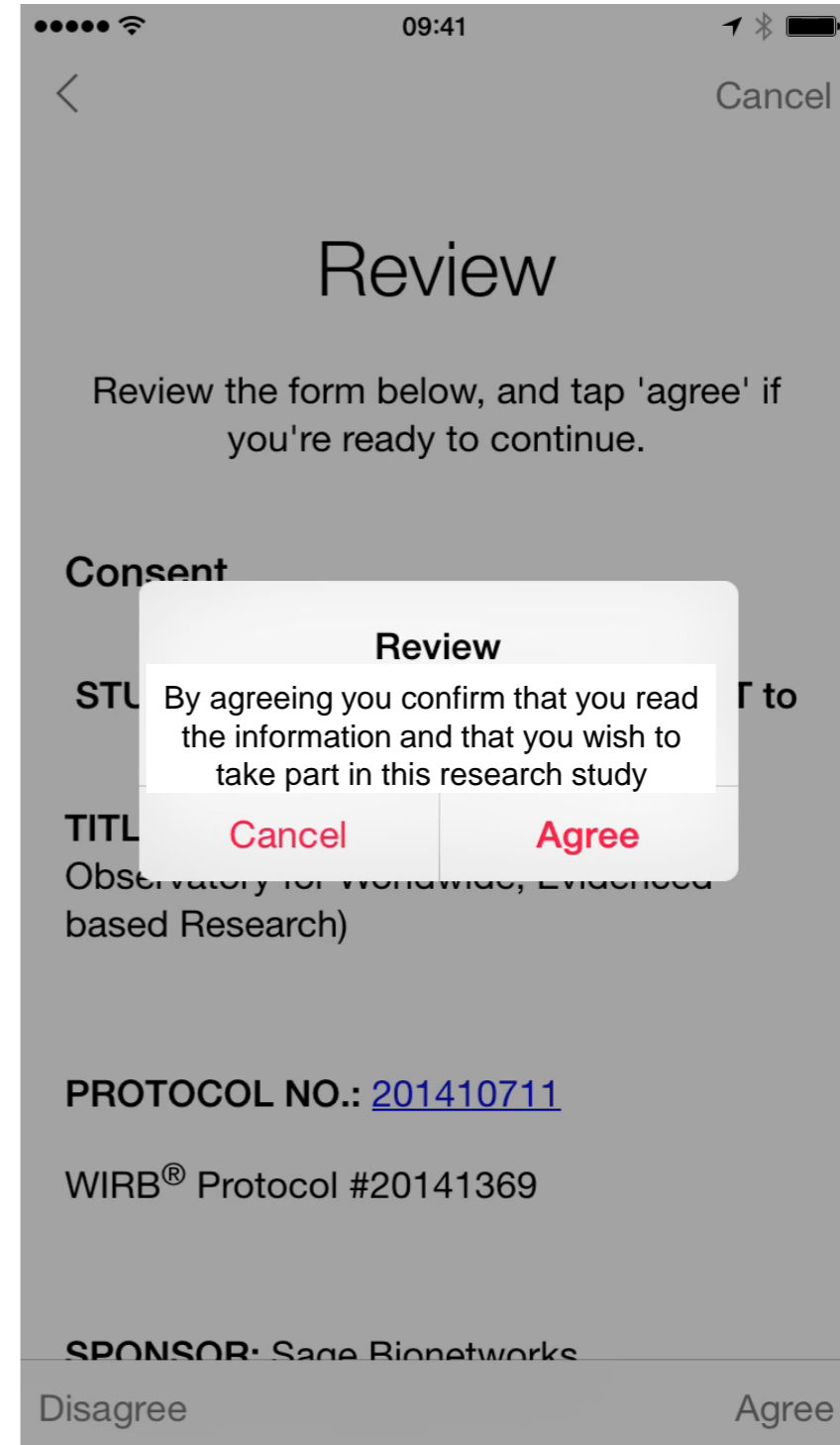
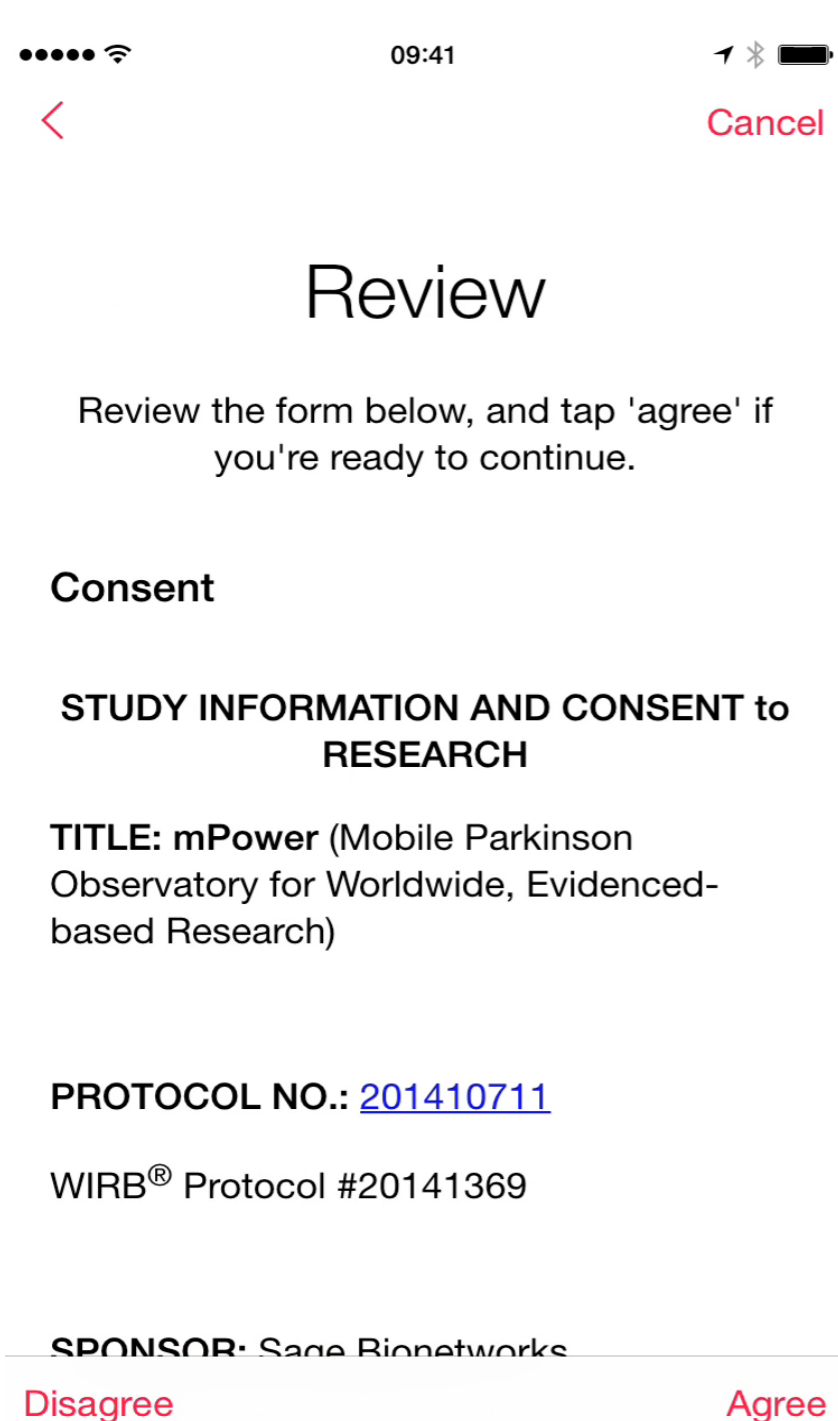



Try Again

Unfortunately you answered one or more questions incorrectly. You can return at the beginning of the walkthrough to get more information about the study.

Next

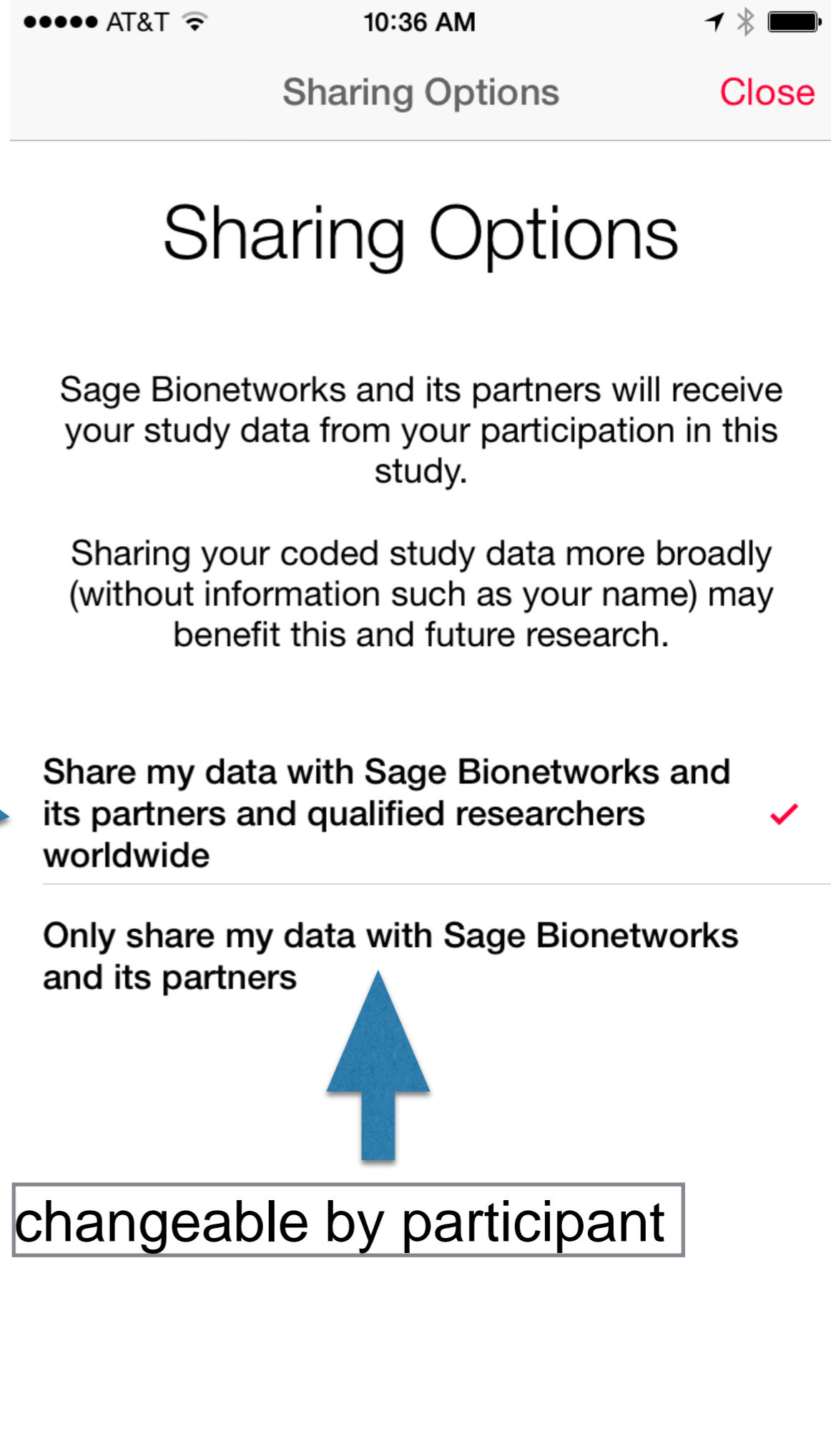
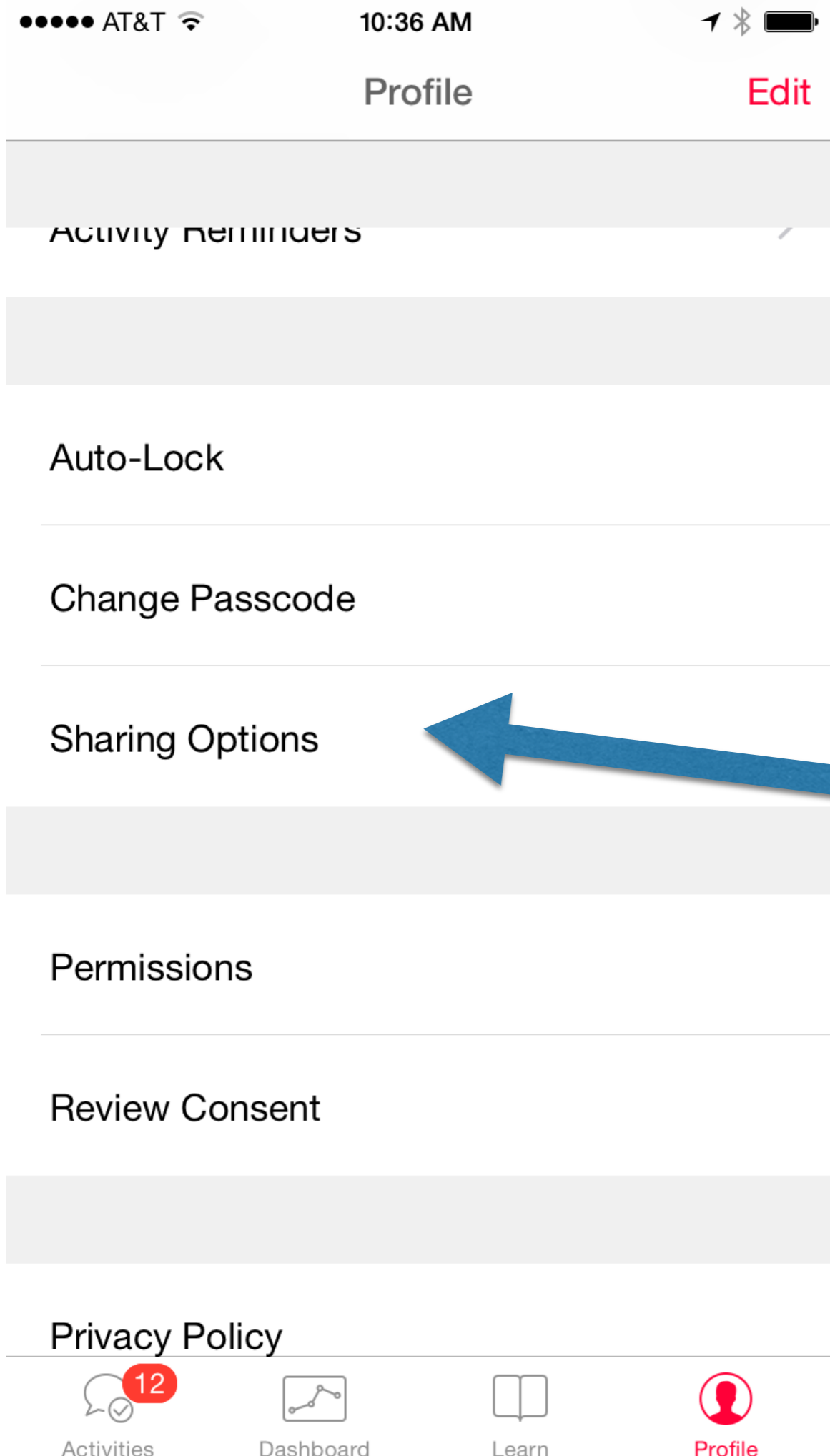
review traditional consent form



unambiguous consent

A mobile app screenshot of a 'Consent' screen. At the top, there is a back arrow on the left, the title 'Consent' in the center, and a 'Cancel' button on the right. Below the title, there are two input fields: 'First Name' with 'Required' in grey text to its right, and 'Last Name' with 'Required' in grey text to its right. At the bottom center, there is a rounded rectangular button labeled 'Next'.

A mobile app screenshot of a 'Signature' screen. At the top, there is a back arrow on the left, the title 'Consent' in the center, and a 'Cancel' button on the right. Below the title, the word 'Signature' is displayed in a large font. Underneath, the text 'Please sign using your finger on the line below.' is centered. A horizontal line is drawn across the screen with the text 'Sign Here' positioned above it. At the bottom center, there is a rounded rectangular button labeled 'Done'.

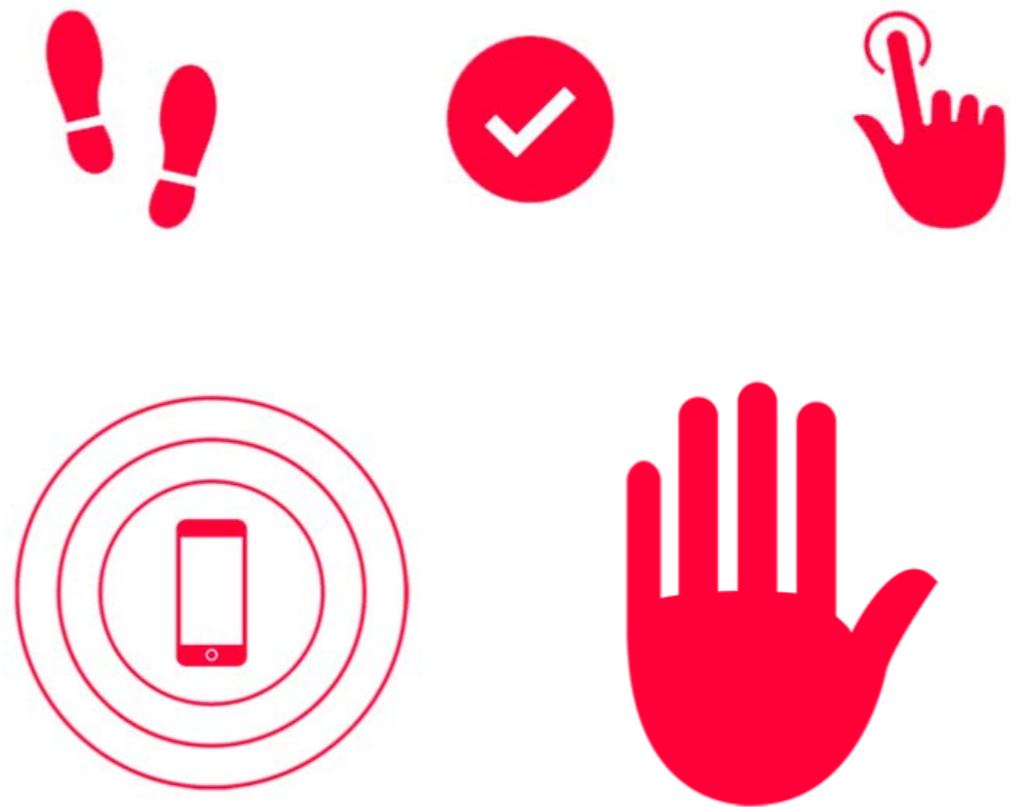


>20,000 mPower enrolled since
3/9/2015

(~75% choose to share broadly)

open source methods

iconographic
representations of
key concepts
in informed
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.

3.

governance beyond consent



GLOBAL ENTRY

TRUSTED TRAVELER NETWORK

GLOBAL ENTRY

TRUSTED TRAVELER NETWORK

GLOBAL ENTRY

TRUSTED TRAVELER NETWORK



U.S. Customs and Border Protection



U.S. Customs and Border Protection



U.S. Customs and Border Protection

First, design for data sharing

John Wilbanks & Stephen H Friend

To upend current barriers to sharing clinical data and insights, we need a framework that not only accounts for choices made by trial participants but also qualifies researchers wishing to access and analyze the data.

This March, Sage Bionetworks (Seattle) began sharing curated data collected from >9,000 participants of mPower, a smartphone-enabled health research study for Parkinson's disease¹. The mPower study is notable as one of the first observational assessments of human health to rapidly achieve scale as a result of its design and execution purely through a smartphone interface². To support this unique study design, we developed a novel electronic informed consent process that includes participant-determined data-sharing preferences. It is through these preferences that the new data—including self-reported outcomes and quantitative sensor data—are shared broadly for secondary analysis. Our hope is that by sharing these data immediately, prior even to our own complete analysis, we will shorten the time to harnessing any utility that this study's data may hold to improve the condition of patients who suffer from this disease.

Turbulent times for data sharing

Our release of mPower comes at a turbulent time in data sharing. The power of data for secondary research is top of mind for many these days. Vice President Joe Biden, in heading President Barack Obama's ambitious cancer 'moonshot', describes data sharing as second only to funding to the success of the effort³. However, this powerful support for data sharing stands in opposition to the opinions of many within the research establishment. To wit, the august *New England Journal of Medicine (NEJM)*'s recent editorial suggesting that those who wish to reuse clinical trial data without the direct participation and approval of the original study team are "research parasites"⁴. In the wake of colliding perspectives on data sharing, we must not lose

John Wilbanks and Stephen H. Friend are at Sage Bionetworks, Seattle, Washington, USA. e-mail: friend@sagebase.org

sight of the scientific and societal ends served by such efforts.

It is important to acknowledge that meaningful data sharing is a nontrivial process that can require substantial investment to ensure that data are shared with sufficient context to guide data users. When data analysis is narrowly targeted to answer a specific and straightforward question—as with many clinical trials—this added effort might not result in improved insights. However, many areas of science, such as genomics, astronomy and high-energy physics, have moved to data collection methods in which large amounts of raw data are potentially of relevance to a wide variety of research questions, but the methodology of moving from raw data to interpretation is itself a subject of active research.

It is our view that the emerging area of mobile health is another such area, and that data sharing has powerful potential to accelerate discovery. Rapid sharing of data from a large-scale observational study, such as mPower, provides a mechanism to distribute the task of developing appropriate analytical methods and identifying the approaches that maximize the utility of this new type of data. As with any new technology, a major obstacle to extracting clinical utility will be the development of useful analytical approaches. By facilitating the rapid and widespread distribution of mobile health data, we hope to entice a community of researchers to evaluate the applicability of a wide range of analytical approaches to achieve meaning from this emerging type of data.

Additionally, as researchers, we have an ethical obligation to participants to maximize the scientific value of their data donation. Our engagement with research participants should be as co-equals in the research ecosystem. Meaningful engagement with participants includes soliciting and honoring participant preferences for the distribution of their donation. Our experience suggests that participants

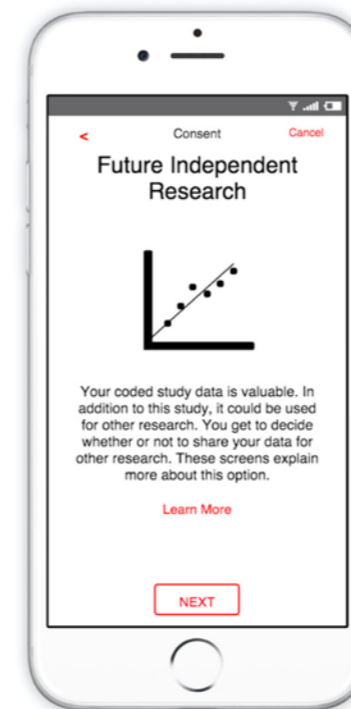
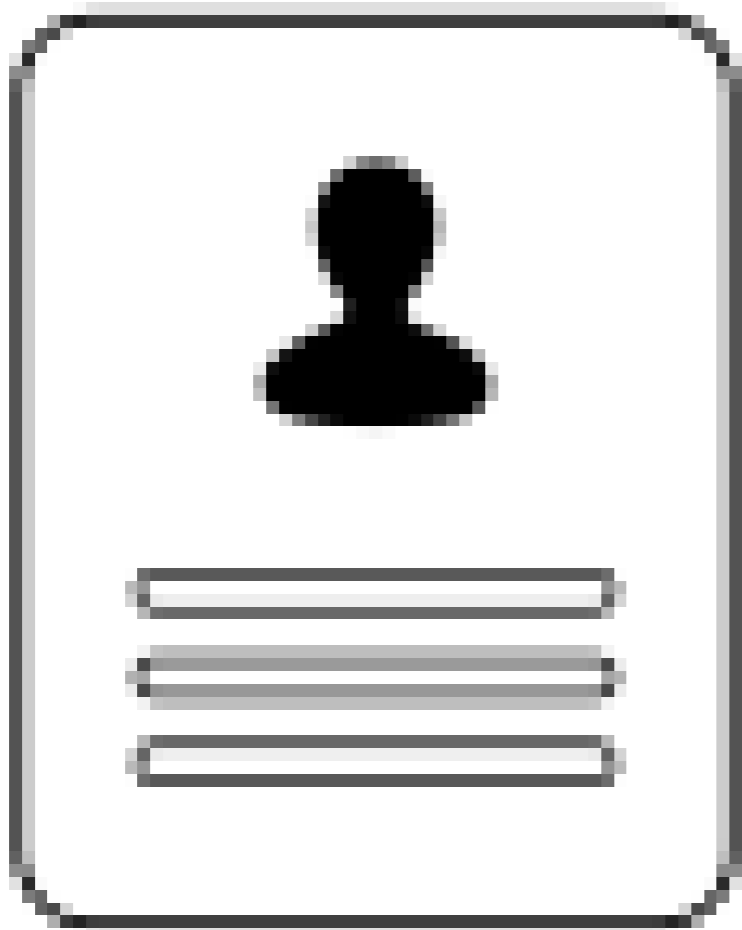


Figure 1 Image of toggle screen in mPower app.

who give their time and their sensitive personal information to researchers often assume that their data will be distributed widely to the full research community, not 'owned' as an asset to extract value from, solely by the researchers who happened to collect it. It is precisely to enable a new class of medical researchers that we at Sage Bionetworks offer participants the choice as to whether or not to share their own study data. In our view, those who would reuse study data are more commonly known as data scientists than parasites, and their reanalysis is to be welcomed.

Qualifying users and empowering participants

To address this misconception head-on, as part of the mPower informed consent, each



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:

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

_____ * 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

thank you

<http://sagebase.org/>

@sagebio

@wilbanks