
research participation as a social contract

our approach

promote open **systems, incentives, and norms**
to redefine how complex biological data is
gathered, shared, and used

sage bionetworks

our focus

engage **diverse communities** of researchers
around biological and analytical problems
too complex for a single institution

empower **citizens** to track their own health
and **contribute** deep phenotypic data to
research topics important to them

sage bionetworks



mPower helps decipher Parkinson's disease.

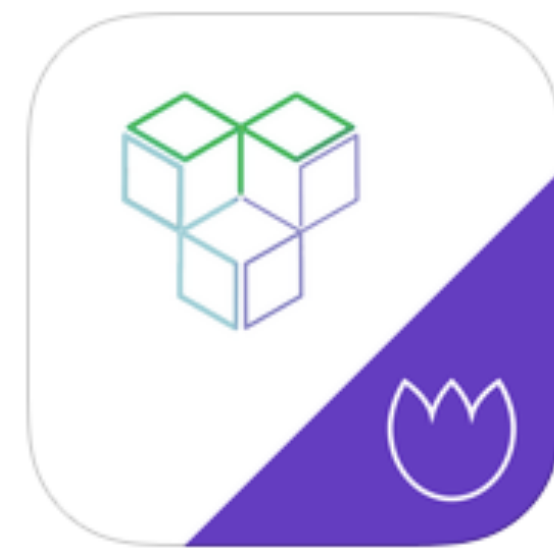
The variability in Parkinson's disease symptoms has left many questions unanswered. So the University of Rochester and Sage Bionetworks created the mPower app to precisely measure data such as dexterity, balance, memory, and gait. This information could help researchers better understand how various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

ResearchKit



It's open source.
So the world can
make the most of it.





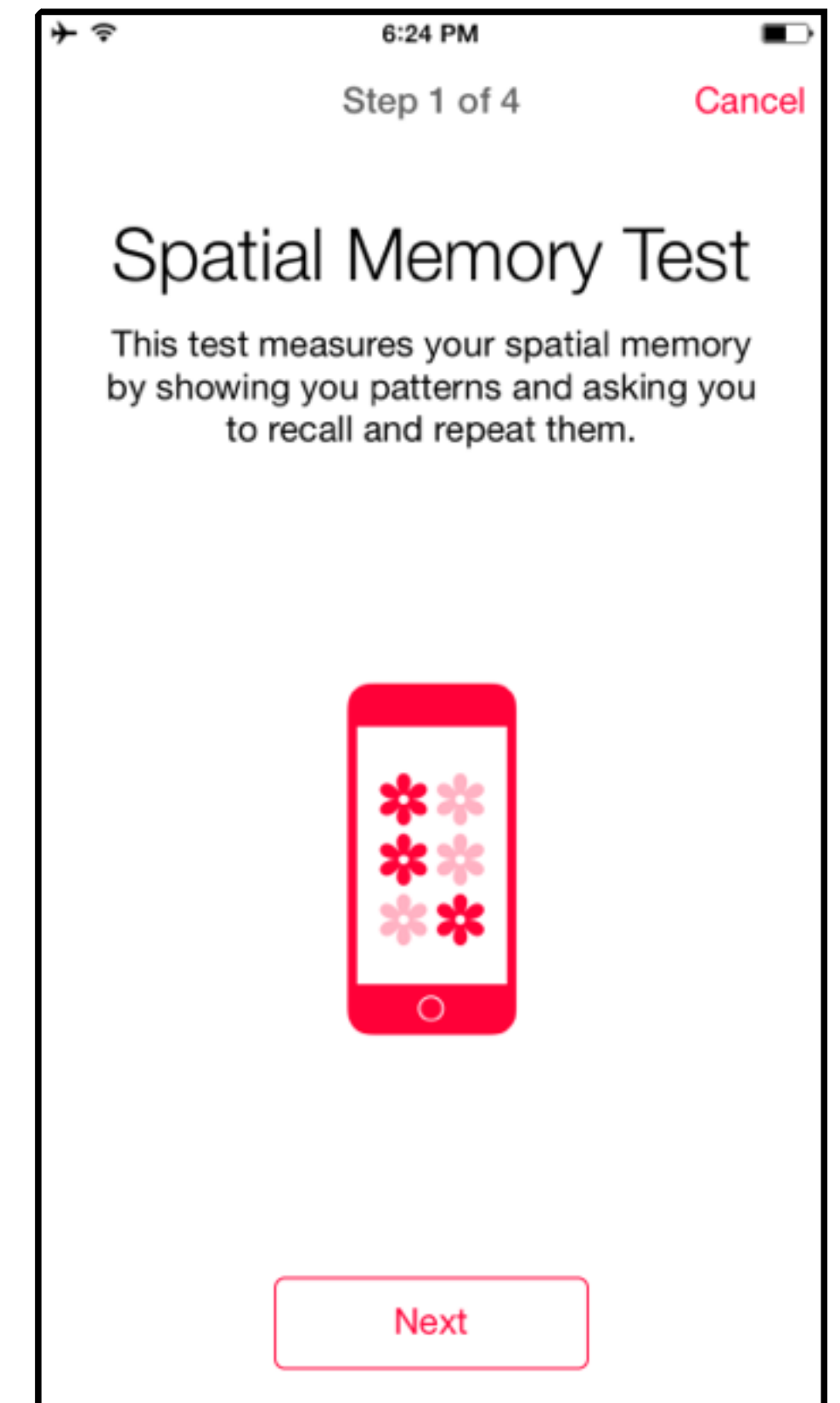
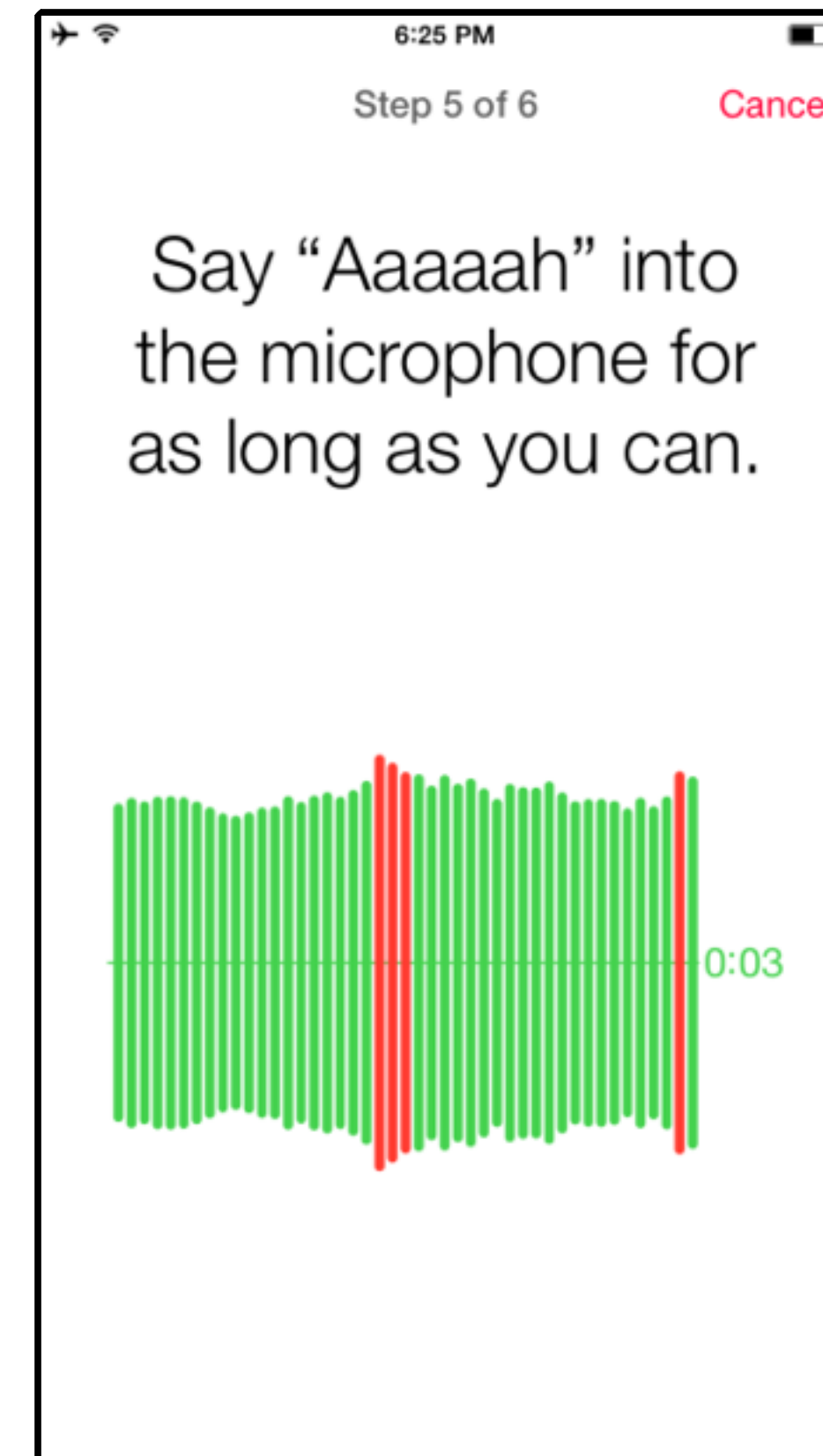
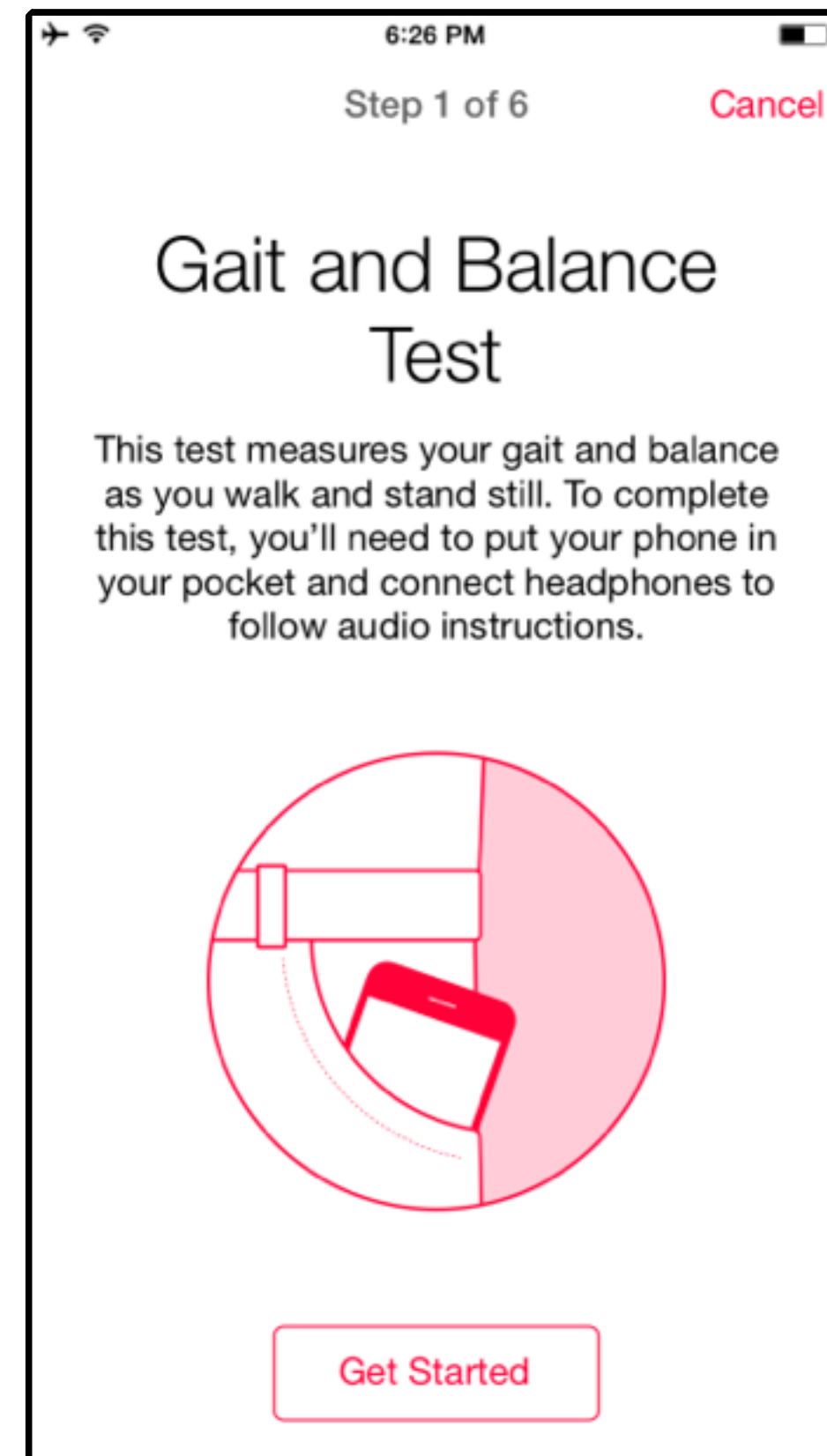
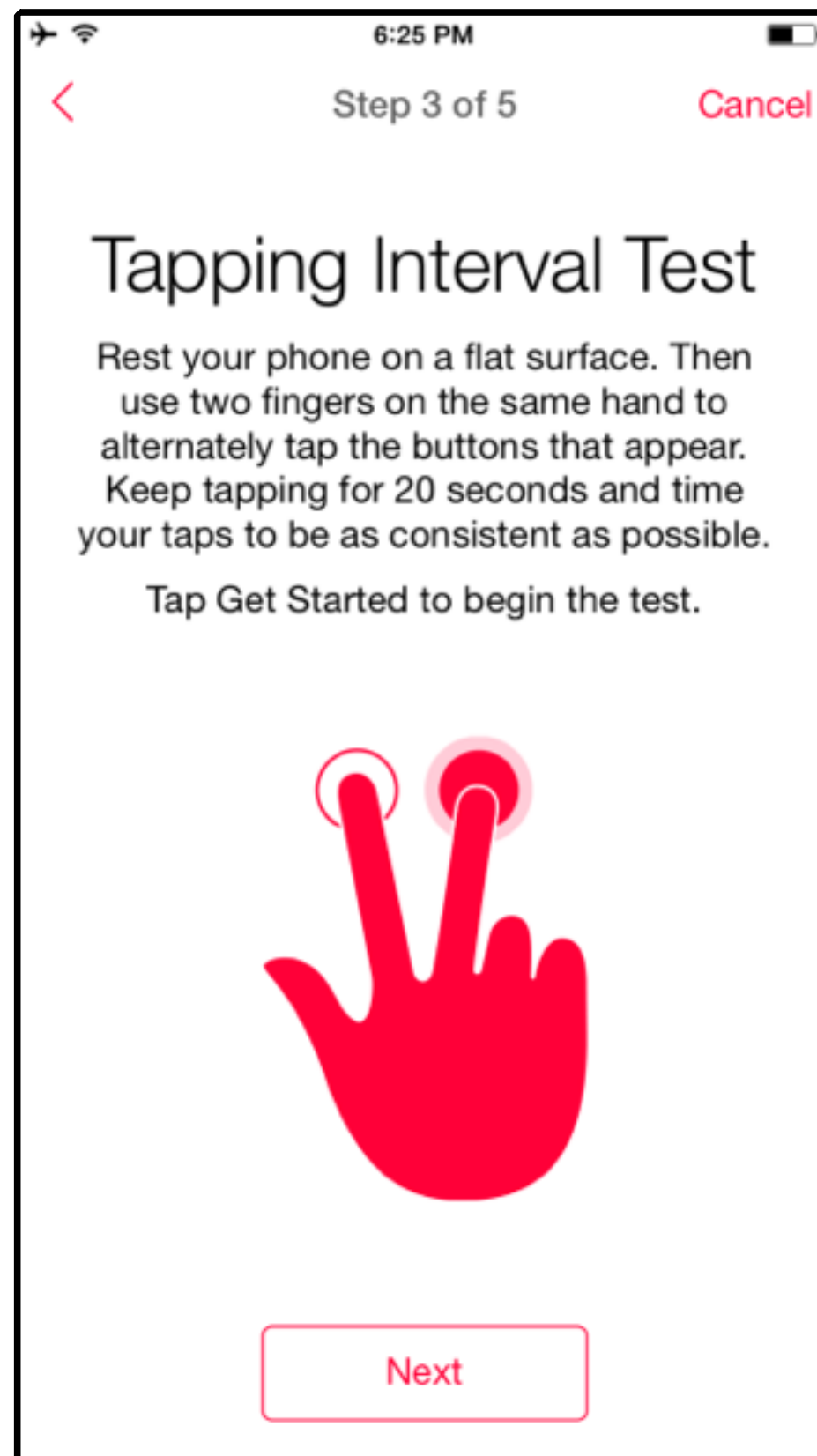
mPower

motor initiation

gait/balance

hypophonia

memory

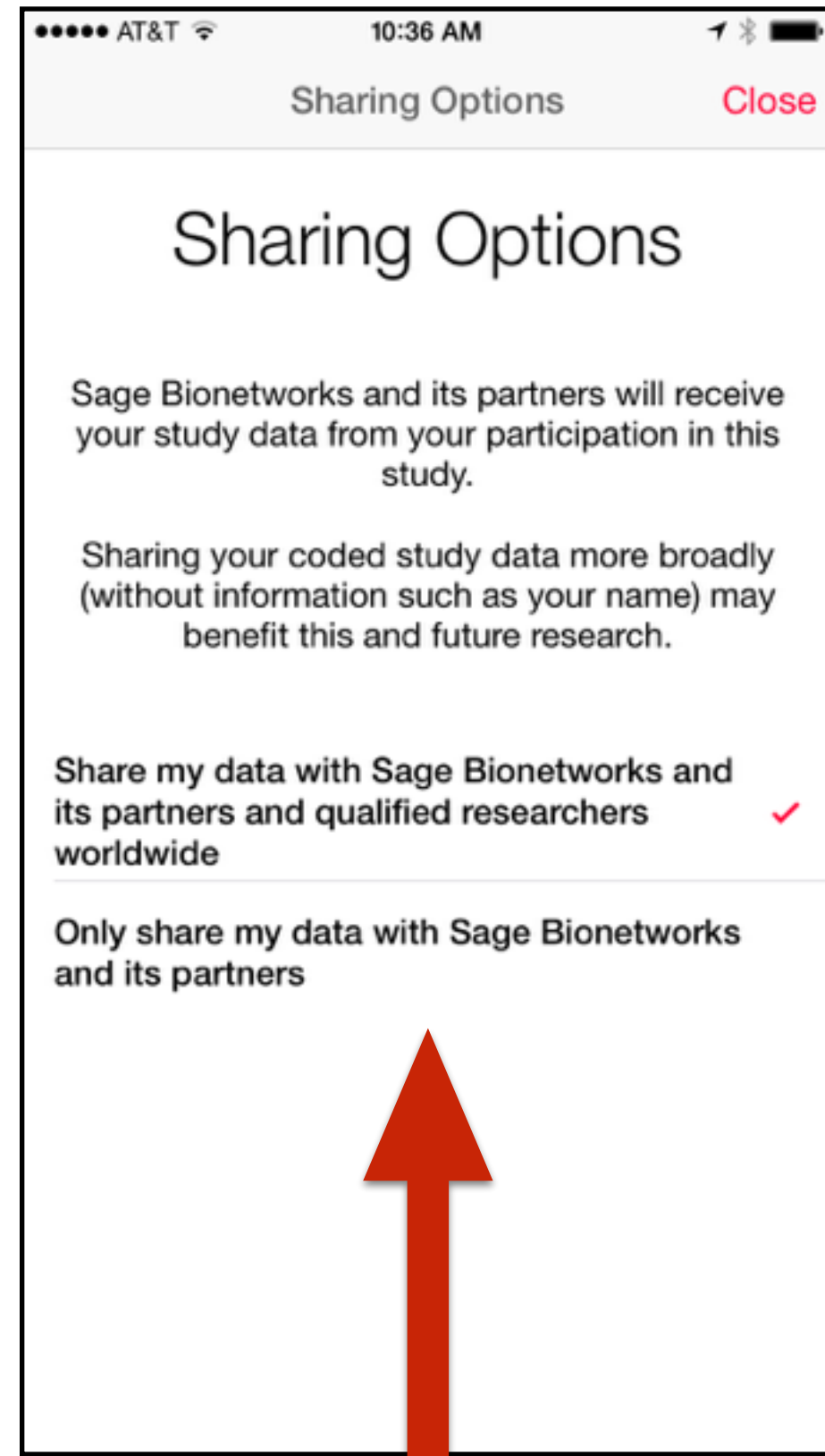
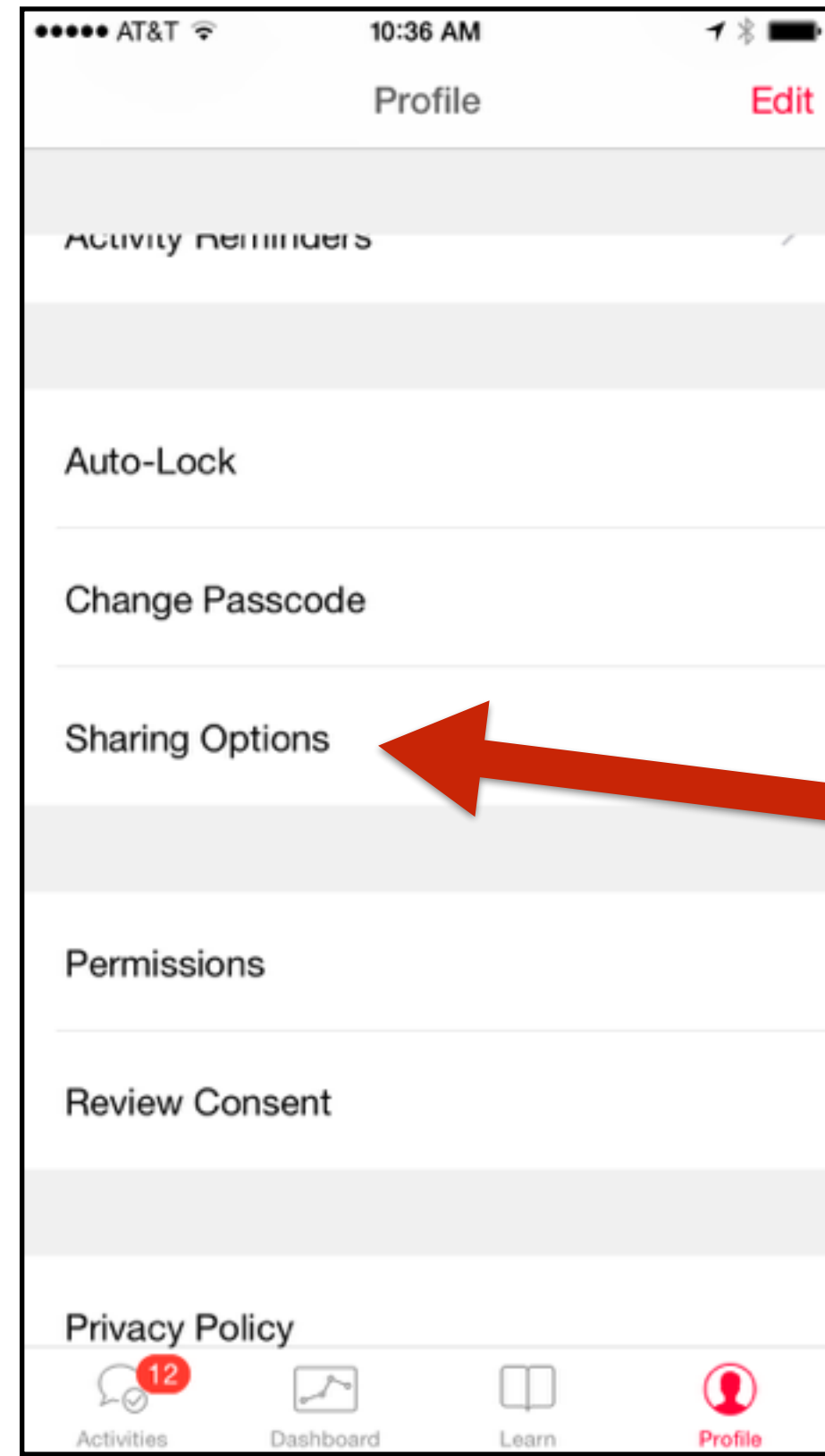
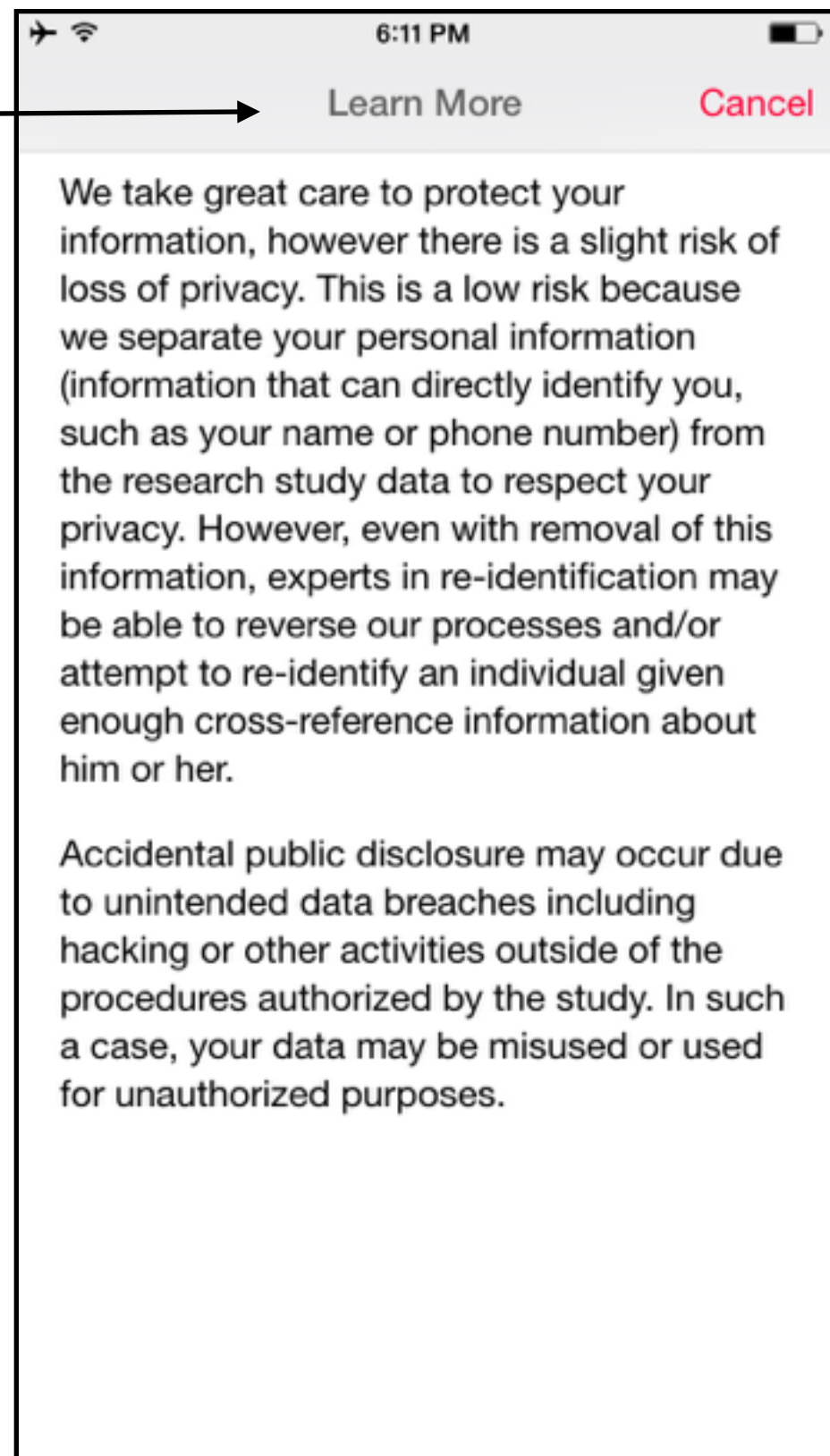
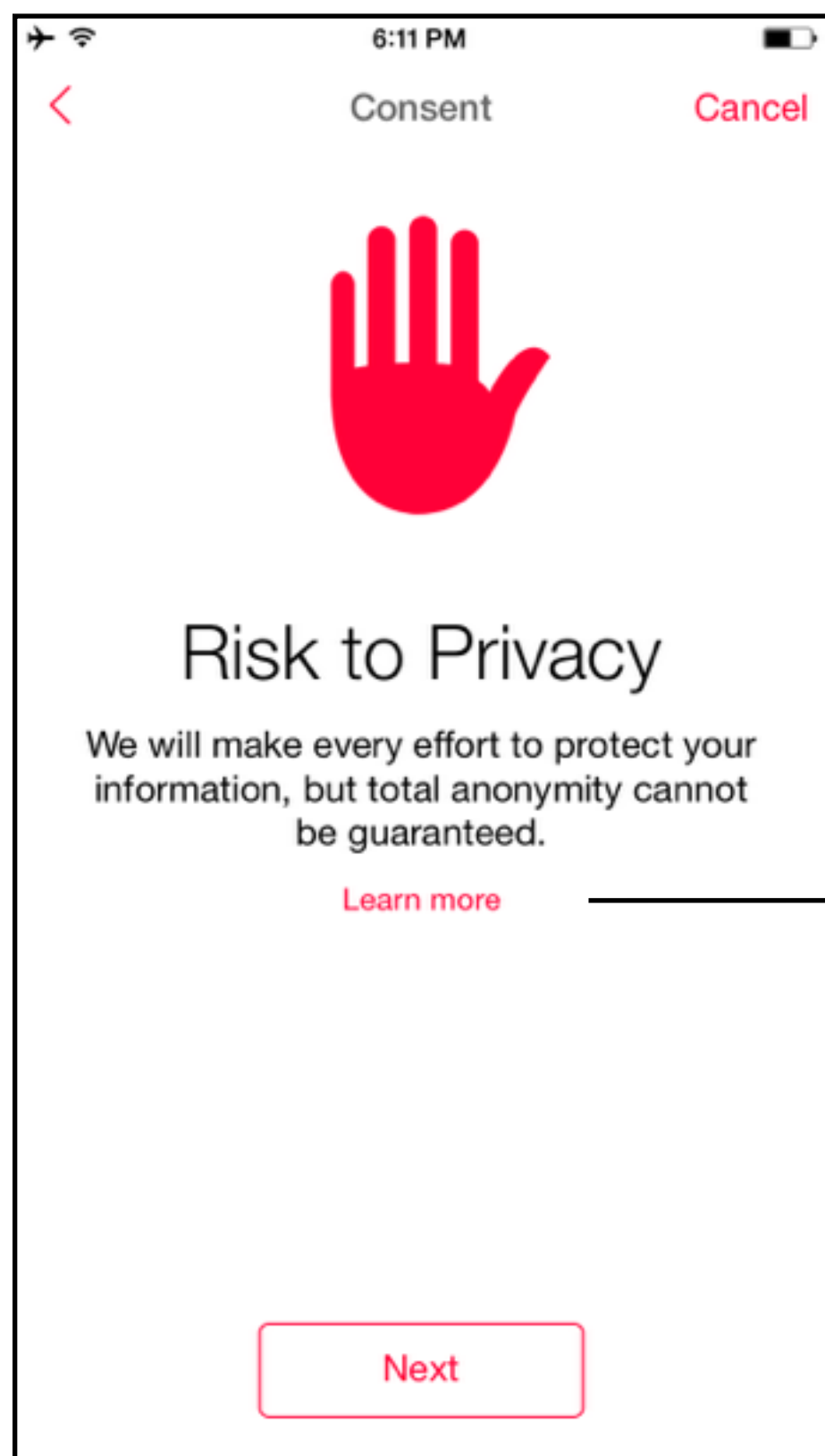




mPower

participant-centered consent

configurable secondary sharing



changeable by participant



mPower

‘qualified researcher’ first pass

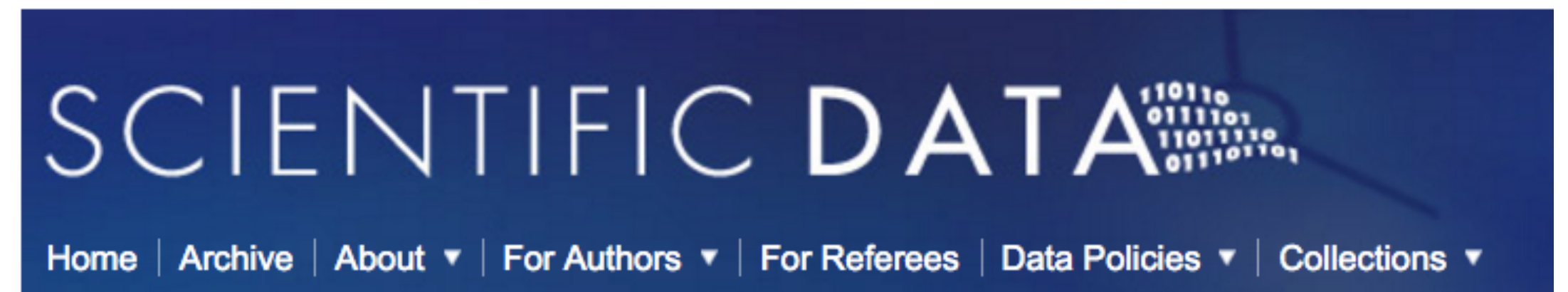
register for a synapse account
get a validated user profile
become a certified synapse user
submit an intended data use statement
agree to the conditions for use
download the data



mPower

‘qualified researcher’ first pass

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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

9,520 unique participants

8,320 completed at least one task

1,087 self reported parkinson diagnosis

198,639 total activities and surveys completed



mPower

seeding a community in PD research

released before any primary publication
60+ independent 'qualified researchers'

'qualified researcher' first pass

register for a synapse account
get a validated user profile
become a certified synapse user
submit an intended data use statement
agree to the conditions for use
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The screenshot shows the mPower Public Researcher Portal on the Synapse platform. The page header includes the portal name, a search bar, and user information for Brian Bot. Below the header, there are navigation tabs for Wiki, Files, and Tables. The main content area is titled "3 - mPower research community" and contains a section titled "Seeding a community in Parkinson research". This section includes a paragraph explaining the goal of the study and a list of projects. Below this, there is a profile for the researcher Brian Bot, including their ORCID and affiliation with Sage Bionetworks. The page also features an "Intended Data Use Statement" section with a date of acceptance.

mPower Public Researcher Portal ☆ Search [] [] Brian Bot (BrianMBot) [] Help [] []

Synapse ID: syn4993293 DOI: doi:10.7303/syn4993293 Upload Destination: Synapse Storage [] Share [] Annotations [] Tools []

Wiki Files Tables

mPower Public Researcher Portal

- 1 - Accessing the mPower data
- 2 - Data description
 - Demographics Survey
 - MDS-UPDRS Survey
 - PDQ-8 Survey
 - Memory Activity
 - Tapping Activity
 - Voice Activity
 - Walking Activity
- 3 - mPower research community
- 4 - Publications
- 5 - FAQs
- 6 - Contact us

mPower Public Researcher... » 3 - mPower research comm...

3 - mPower research community

Seeding a community in Parkinson research

There are now 45 approved projects leveraging the data shared broadly by mPower study participant. It is the hope of Sage Bionetworks that by participants making their data available to qualified researchers worldwide, that we can seed a community who will work together and share insights into Parkinson symptoms and modulators. Synapse Certified Users with verified profiles may request access to the mPower data resource for research to benefit human health. Below is a listing of all projects leveraging the mPower data. Take a look at what others are proposing to do, and reach out to any who you may be interested in working with!

Researcher: Brian Bot ([profile](#))

ORCID: <http://orcid.org/0000-0002-2412-6826>

Affiliation: Sage Bionetworks

Intended Data Use Statement (accepted on 2016-01-27):

In March 2015, as a member of the research team at Sage Bionetworks, we launched mPower (<https://github.com/Sage-Bionetworks/mPower>), an observational smartphone-based study developed using Apple's ResearchKit library (<http://researchkit.org/>). The goal of our study is to evaluate the feasibility of remotely collecting frequent information about the daily changes in symptom severity and their sensitivity to medication in Parkinson disease (PD). These data provide the ability to explore classification of control participants and those who self-report having PD, as well as to begin to measure the severity of PD for those with the disease. There are myriad additional questions from each of the varying streams of data that will require a community of researchers to explore fully.

thank you

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