



The Brain Health Registry:

An Internet-Based Registry

Recruitment, Assessment, & Longitudinal Monitoring
for Clinical Neuroscience Research

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GOALS

- To reduce costs of AD clinical trials
 - An on line registry for recruitment, screening, and monitoring progression
 - Available to investigators for all types of neuroscience studies
- To establish a large cohort of elders who are monitored longitudinally
- Specifically, to develop on-line tests who indicate elders at risk for AD
- Evidence supporting the feasibility of this approach

PROBLEMS WITH ONLINE COHORTS

- Concerns about:
 - Privacy
 - Reliability
 - Validity
 - Generalizability
 - Feasibility: **Biggest Problem**
- These concerns must be addressed

WHY ANOTHER REGISTRY?

- There are a number of existing registries, and new ones are being created
- What is unique about the Brain Health Registry?
 - Not limited to Alzheimer's disease
 - Solicits registration of all ages, no excludes
 - Extensive questionnaires
 - Neuropsychological tests: Cogstate, Lumos
 - Advertised by Lumosity: we have their data
 - Available to many investigators

YOU CAN HELP SAVE LIVES

You can participate in a groundbreaking project to help find cures for Alzheimer's, Parkinson's, depression and other brain disorders. And you can do it all online.



It's safe, easy and free.

JOIN NOW



Anne de la Rosa

"My college roommate was recently diagnosed with Parkinson's. She's working hard - exercising, meditating, doing yoga - to keep her symptoms at bay, and she's holding on to the positive attitude she's always had. I'm hoping this research can lead to a cure and help her stay positive and vital. That's why I'm here."

— Anne de la Rosa
San Mateo, CA



Oakland A's Pitcher Sean Doolittle Records PSA on the Brain Health Registry

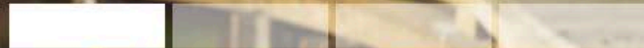
[Listen to the PSA.](#)

Brain Health Registry Receives Certificate of Honor from SF Mayor Edwin Lee

[View the Certificate](#)

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ANSWER QUESTIONS & PLAY GAMES

When you play simple online games, we get “snapshots” of your health and brain performance. With many snapshots, from you and others, we can make a huge difference.

[See How It Works »](#)

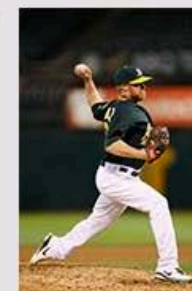
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“I’ve seen the impact of Alzheimer’s – I’ve had friends who have lost loved ones, and the toll is immense. So I see it as a privilege to help with medical research. I feel like this is a way I can pay it forward to future generations, including my own children.”

— Jackie Boberg
Saratoga, CA



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Brain Health Registry Receives

ANSWER QUESTIONS & PLAY GAMES

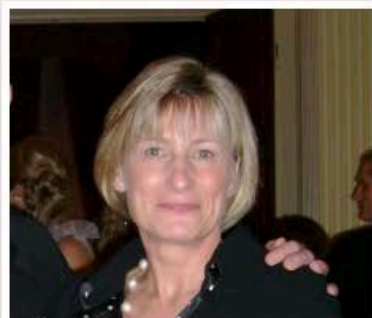
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It's

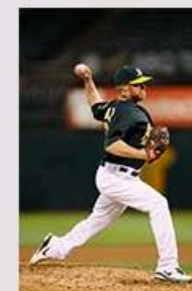
25%

JOIN NOW



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Brain Health Registry Receives

✓ **Medical History****Early History**

(5 min)

✓ **Diet****Everyday Cognition**

(10 min)

✓ **Family Tree****Current Medications**

(5 min)

Your medical history may provide important insight into potential influences on your current brain health. All information you provide remains private.

This section includes a set of health-related questionnaires. Next to each questionnaire, you can see its anticipated duration. After completing a questionnaire, you will see a check mark.

We strongly encourage you to complete all the questionnaires, and please do so at your own pace.

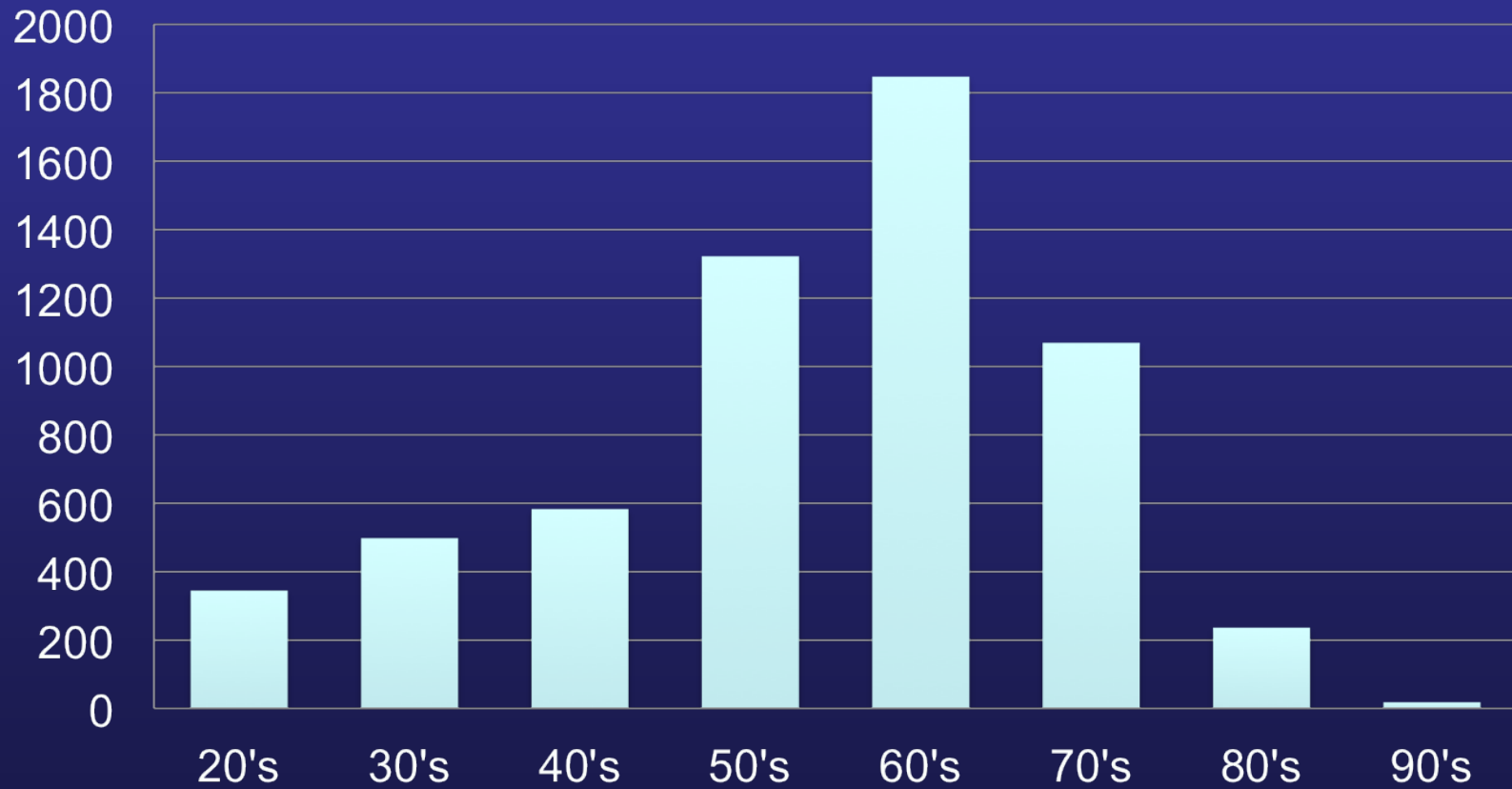
By answering all the questions, you are helping us develop a better understanding of the human brain.



Registry questionnaires:

- Personal medical history
- Family medical history
- Diet, sleep, exercise, lifestyle
- Basis for questionnaires:
 - Geriatric Depression Scale (GDS)
 - Everyday Cognition Scale (Ecog)
 - Short Form Health Survey (SF-36)
 - Pittsburgh Sleep Quality Index (PSQI)

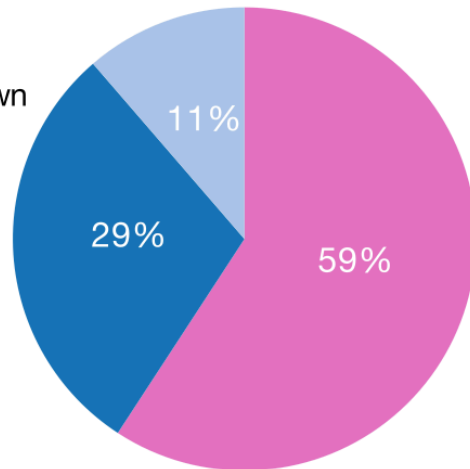
Age, current members: approx. 7000



Dashboard: Initial figures

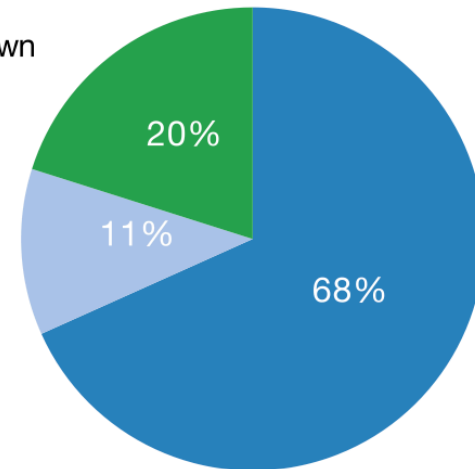
Gender

- Female
- Male
- Unknown



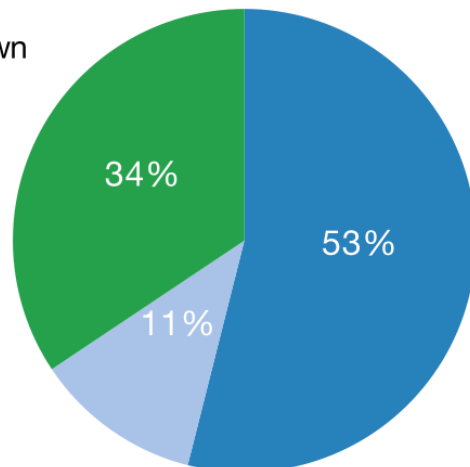
Family History of Alzheimer's

- No
- Unknown
- Yes



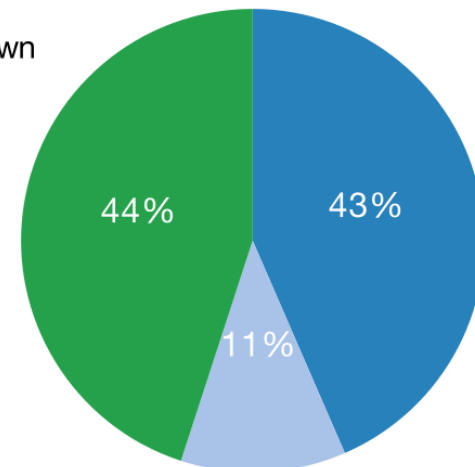
Memory Concern

- No
- Unknown
- Yes

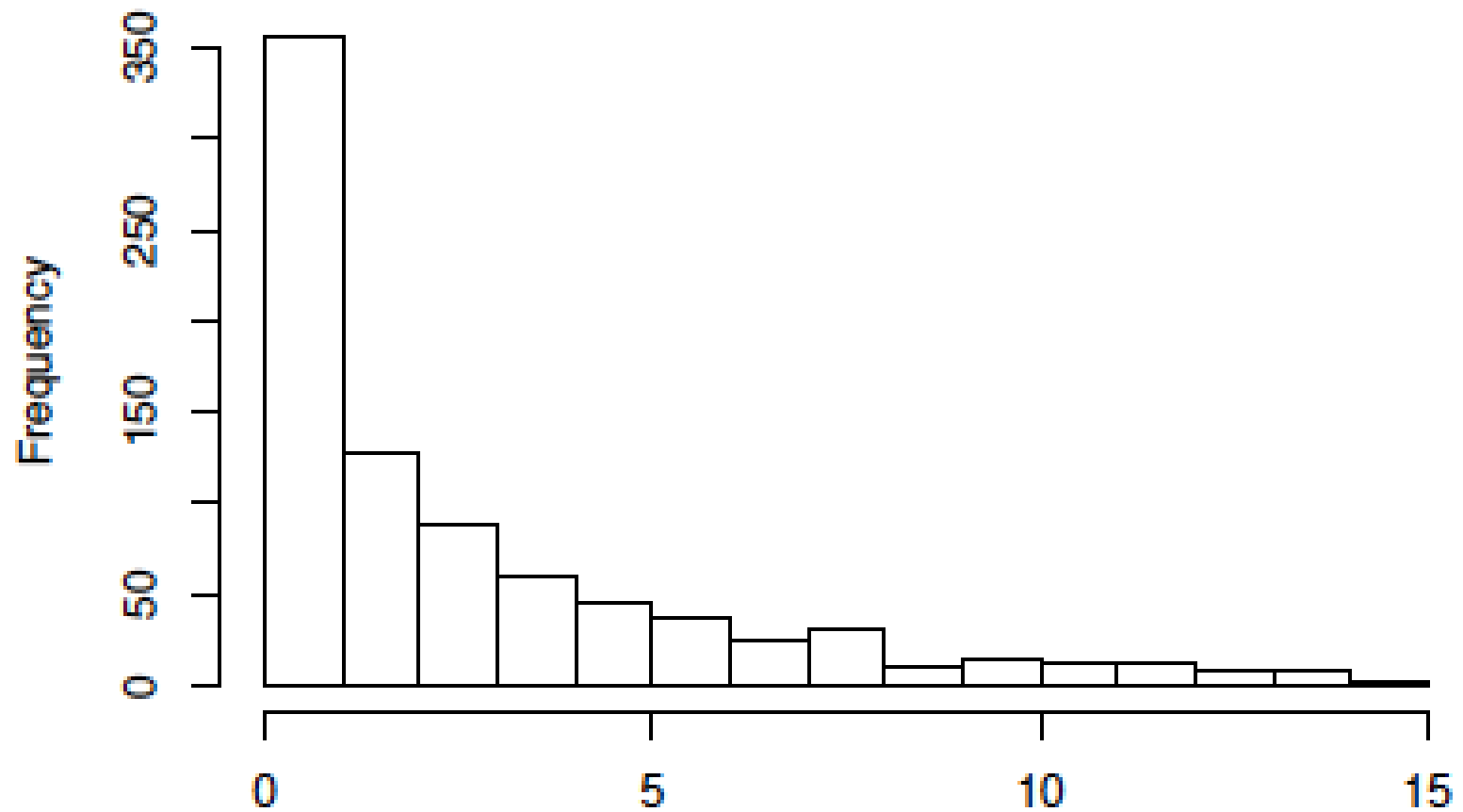


Sleep Problems

- No
- Unknown
- Yes



Geriatric Depression Scale:



Key partner: Cogstate



The image is a screenshot of the Cogstate website. At the top, there is a navigation bar with the Cogstate logo on the left and links for ABOUT, INVESTORS, DIRECTORS, NEWS, and CONTACT on the right. Below the navigation bar is a large blue banner with a faint image of a human brain. The banner contains the text "THE GLOBAL LEADER IN ASSESSING, MONITORING AND IMPROVING COGNITION" in white, followed by "ASSESS · MONITOR · IMPROVE" in a smaller font. Below the banner are four white boxes, each representing a different sector: CLINICAL TRIALS, HEALTHCARE, ACADEMIC, and SPORTS. Each box contains a brief description of Cogstate's role in that sector, a hexagonal icon with a white plus sign, and a logo for a partner organization at the bottom. The partner logos are: COGSTATE CT CLINICAL TRIALS, COGNIGRAM, COGSTATE RESEARCH, and AXON SPORTS.

COGSTATE

ABOUT INVESTORS DIRECTORS NEWS CONTACT

THE GLOBAL LEADER IN ASSESSING,
MONITORING AND IMPROVING COGNITION

ASSESS · MONITOR · IMPROVE

CLINICAL TRIALS

Scientists rely on Cogstate to help them develop and improve new pharmaceuticals

HEALTHCARE

Physicians trust Cogstate to assess and report on the cognitive function of their patients

ACADEMIC

Researchers collaborate with Cogstate to learn about cognitive disease and treatment

SPORTS

Athletes team up with Cogstate to protect and train their athletic brain

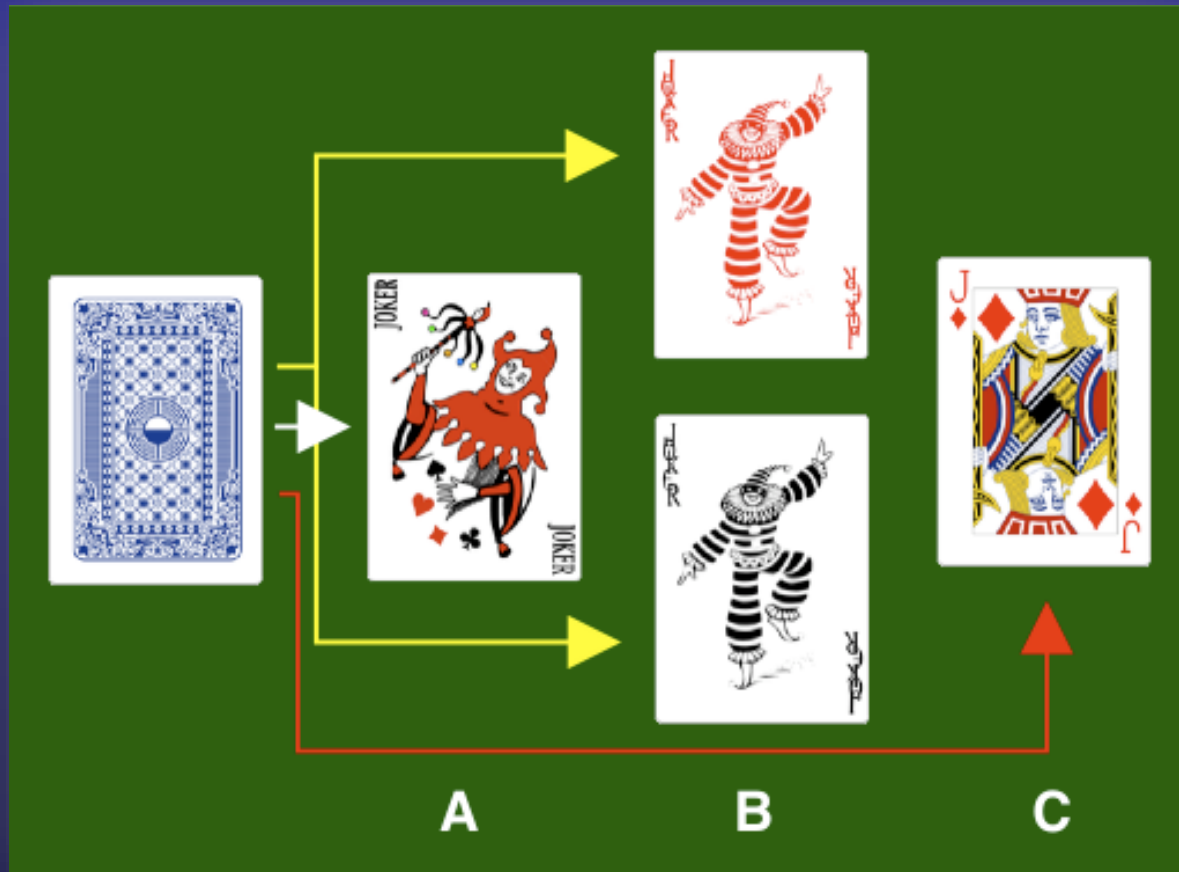
COGSTATE CT
CLINICAL TRIALS

COGNIGRAM

COGSTATE
RESEARCH

AXON SPORTS

Cogstate card test



- A. Simple Reaction time task
- B. Choice RT task
- C. 1-card learning & 1-card back tasks

COGSTATE RESULTS

- Currently approx 3500 cogstate results
- Scores exactly coincide with age adjusted norms from Cogstate in-clinic subjects
- Age related reduction in subjects over 60
- Reduced cognition in those with complaints
- Overall the results are extremely encouraging: in-clinic validation is funded

Lumosity: Sharing tests and data

lumosity

HUMAN COGNITION PROJECT

USER STORIES

START TRAINING

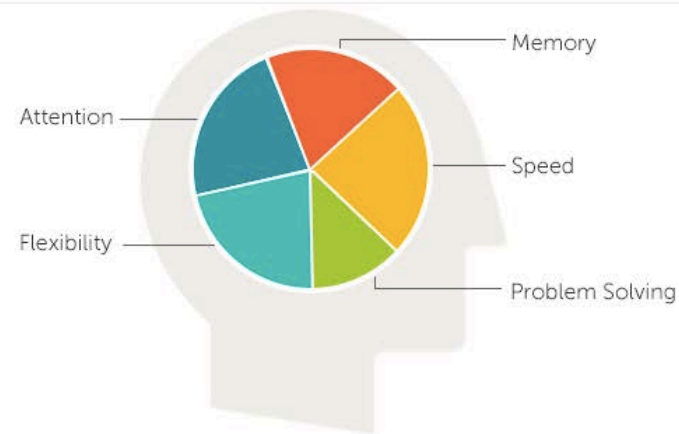
LOG IN

Improve your brain performance and live a better life

Build your Personalized Training Program

- Enhance memory and attention
- Web-based personalized training program
- Track changes in your performance

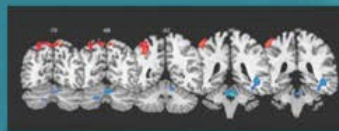
Get Started Now →



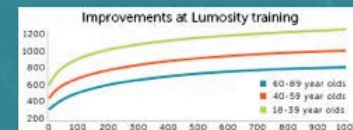
The Science Behind Lumosity



Lumosity exercises are designed by neuroscientists to improve core cognitive

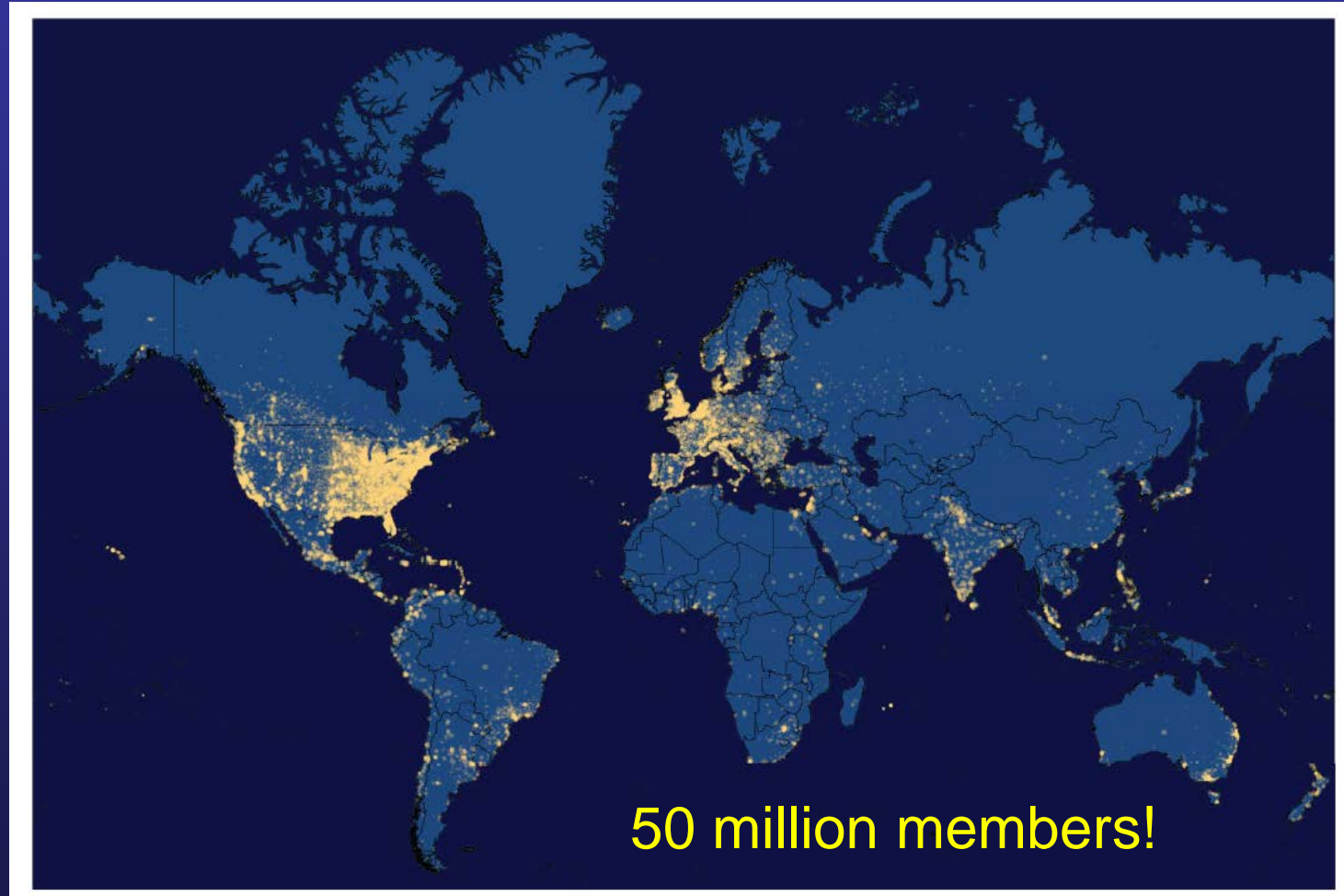


Researchers have measured improvements in working memory and attention after



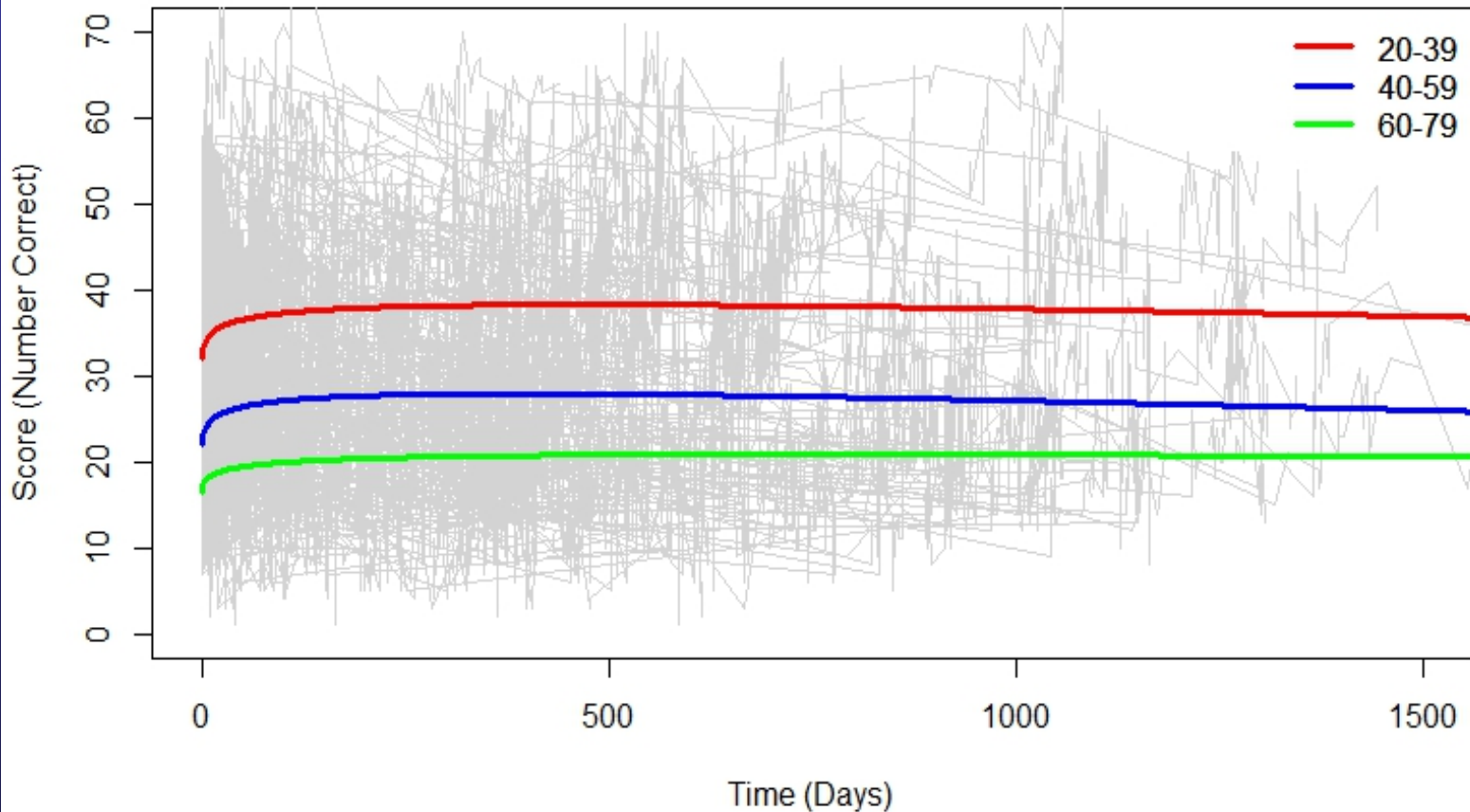
Dozens of research collaborators help us to improve the Lumosity training

Lumosity: Also sharing contacts

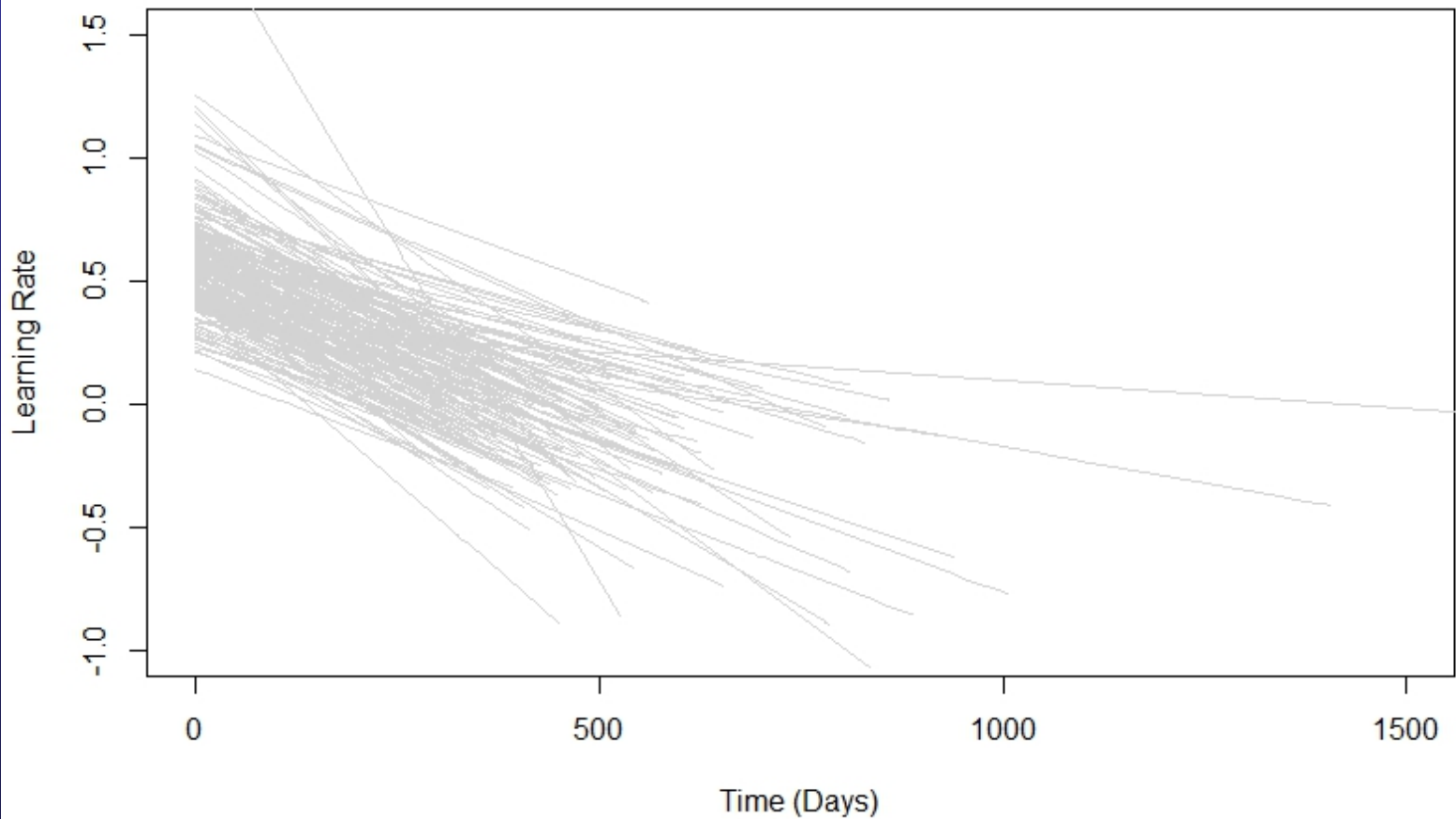


A map of users' locations based on their IP address

Memory Match Game Score



LOWER 25TH OF DECLINING ELDERS LEARNING RATE BY TIME



SIMULATED TRIAL RESULTS

Lower quartile of subjects

Power to detect a 25% attenuation of
learning rate decline

- 80% power, 5% significance
- Sample Size : 110 per arm
- These results support the concept of using prior game score data to predict future decline and enroll subjects into trials

HOW TO BE INVOLVED

- For help with subject recruitment, contact me
 - Michael.Weiner@ucsf.edu
- An “investigator’s portal” will be available
 - To access data, to identify subjects for your studies
 - Can perform targeted recruitment for your study
- You can develop new studies
 - Which are completely on line
 - Which take advantage of this portal
- You can write grant proposal which use this portal
- You can pilot on-line assessment for clinical use

CONCLUSION

- Use of the internet will facilitate AD clinical trials
- Establishing a large cohort of subjects followed longitudinally will assist recruitment, reduce costs, and improve statistical power of AD trials
- Problems of feasibility, reliability, validity, and generalizability need to be addressed
- This new approach has great promise to accelerate progress in AD research
- We wish to work with academic/industry partners
- We hope to partner with NIA and ADCs



www.TheBrainHealthRegistry.org

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