Remote Assessments: Web-based, App-based, Use Case-based

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Use Case is Key for Considering Data Collection Approaches: *What are our goals?*

Why - To mitigate loss of NACC UDS data because C-19 mandates a need for physically distanced UDS assessments; AND possible novel digital assessments in the future

What – Remote assessments of…

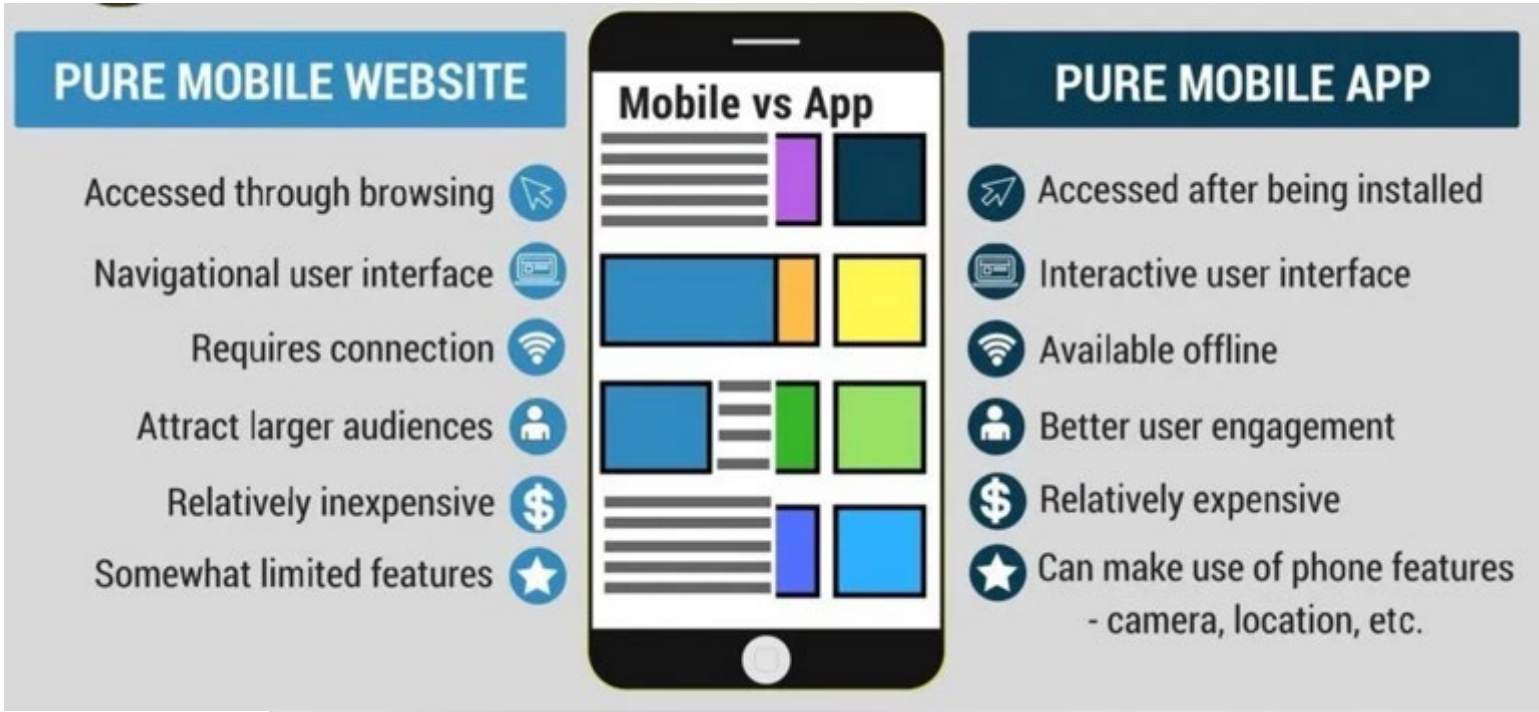
- *"Are you ok"?*
- Portions of UDS (Forms XYZ, Cognition)
- Entire UDS
- Novel functions (time asleep, out of home, life events, physiologic function, etc.)

When - Baseline, follow-up (episodic to continuous)

Who - the ADRCs heterogenous population (15,555 active in database) and the ADRCs research staff

How - Approach should be driven by careful consideration of the above: short-term and longer-term solutions

Mobile Device (mobile app) vs ‘Sedentary’ Device (Web- based) Data Collection → *Why do you want to use a particular method?*



Assessment approach is determined by use case and desired features (user experience, development time, cost, etc.)

S9Digital - https://tinyurl.com/y9mbtzaq
Audit microsystems-https://tinyurl.com/yal3swgf

ADRC Cohort Characteristics Affecting Digital Assessments

- How many are online?
- Who and where are they?
- What devices might they have and use?
- How proficient are they (participants *and* staff) in their use?
- No systematic data available for ADRCs

National Alzheimer's Coordinating Center
Uniform Data Set (UDS)
DEMOGRAPHICS and DIAGNOSES

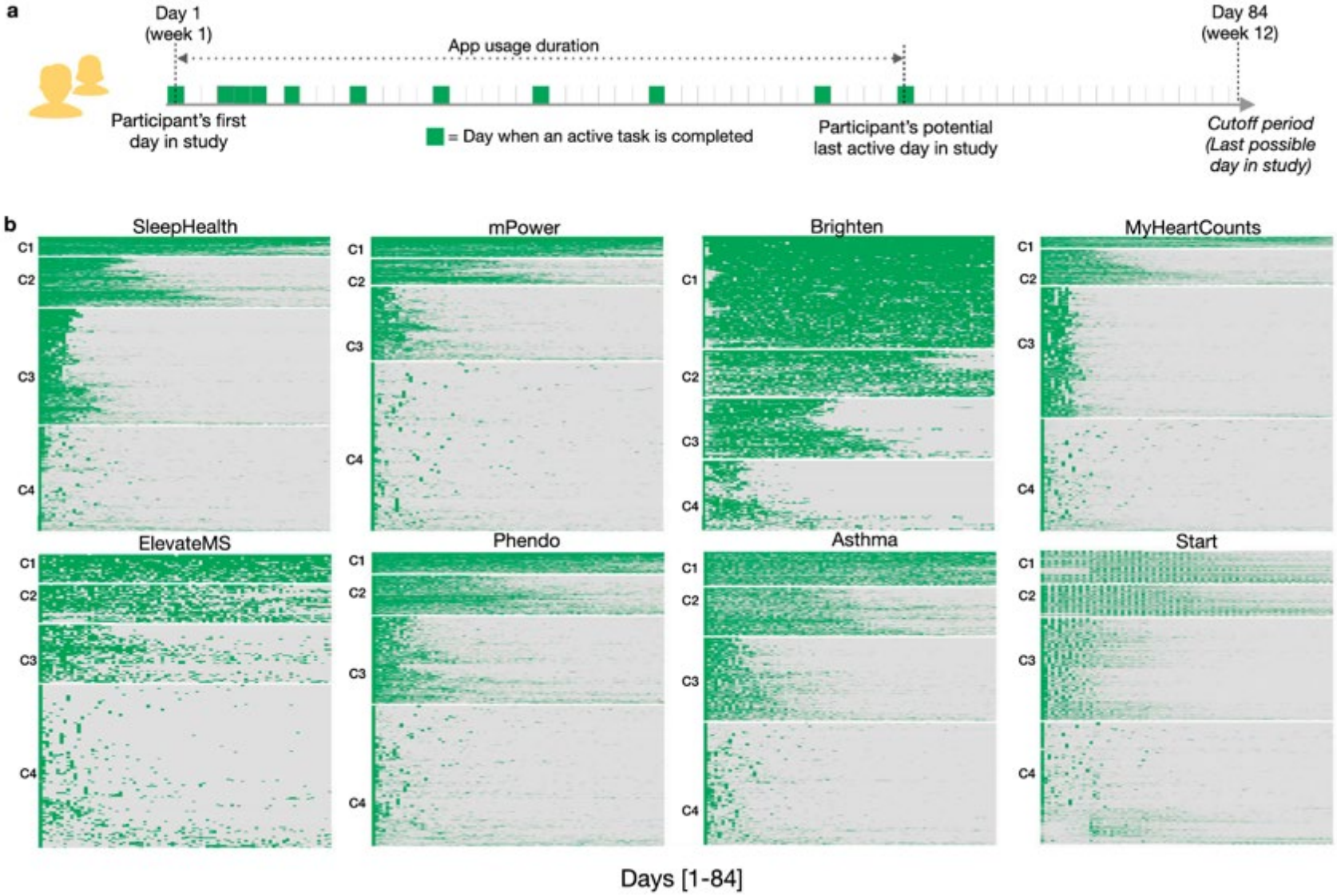
March 2020

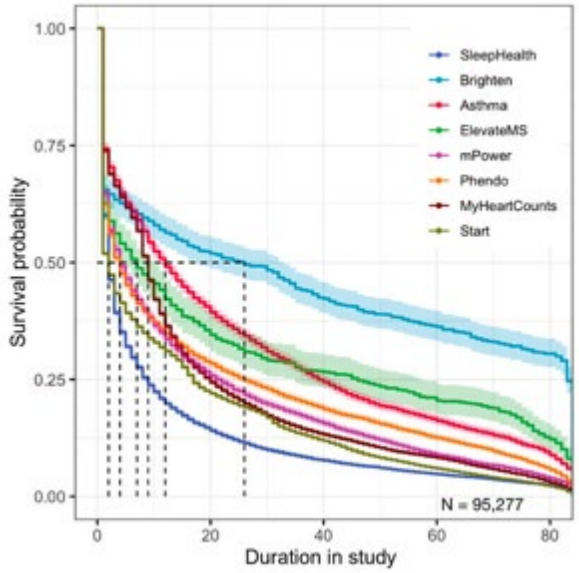
Table 1. UDS subject demographics by cognitive status

	UDS subjects								
	Normal cognition		Impaired, not MCI		MCI		Dementia		All
	n	%	n	%	n	%	n	%	n
Age (y)									
<65	2857	19%	333	19%	988	13%	2871	16%	7049
65-84	10097	67%	1208	68%	5026	67%	11362	62%	27693
>=85	2154	14%	241	14%	1467	20%	4057	22%	7919
Mean (SD)	72.8	(11.4)	73.2	(10.7)	75.7	(10.2)	75.9	(10.8)	74.7
Education (y)									
<=12	2605	17%	507	28%	1972	26%	6046	33%	11130
13-16	6455	43%	724	41%	3013	40%	7141	39%	17333
>=17	5967	39%	547	31%	2438	33%	4901	27%	13853
Missing	81	<1%	4	<1%	58	<1%	202	1%	345
Sex									
Male	5293	35%	726	41%	3511	47%	8723	48%	18253
Female	9815	65%	1056	59%	3970	53%	9567	52%	24408
Race									
White	11714	78%	1264	71%	5686	76%	15185	83%	33849
Black or African American	2189	14%	316	18%	1118	15%	1733	9%	5356
American Indian or Alaska Native	88	<1%	11	<1%	59	<1%	101	<1%	259
Native Hawaiian or Pacific Islander	9	<1%	3	<1%	5	<1%	15	<1%	32
Asian	428	3%	45	3%	231	3%	384	2%	1088
Multiracial	508	3%	78	4%	263	4%	487	3%	1336
Unknown or ambiguous	172	1%	65	4%	119	2%	385	2%	741
Hispanic ethnicity									
No	13991	93%	1541	86%	6709	90%	16776	92%	39017
Yes	1040	7%	240	13%	737	10%	1438	8%	3455
Missing/Unknown	77	<1%	1	<1%	35	<1%	76	<1%	189
APOE									
No e4 allele	7605	50%	856	48%	2959	40%	6371	35%	17791
1 copy of e4 allele	2898	19%	339	19%	1533	20%	5407	30%	10177
2 copies of e4 allele	299	2%	32	2%	265	4%	1417	8%	2013
Missing or unknown or not assessed	4306	29%	555	31%	2724	36%	5095	28%	12680
Number of visits									
1	4081	27%	616	35%	2898	39%	5954	33%	13549
2	2540	17%	282	16%	1469	20%	3509	19%	7800
>=3	8487	56%	884	50%	3114	42%	8827	48%	21312
Mean (SD)	4.1	(3.3)	3.6	(3.1)	3.2	(2.9)	3.2	(2.5)	3.5
Total	15108		1782		7481		18290		42661

Remote assessment with smartphone apps - 😱

>50% OF THE COHORTS CEASED ENGAGEMENT AFTER 12 DAYS





Pratap, A., Neto, E.C., Snyder, P. *et al.* Indicators of retention in remote digital health studies: a cross-study evaluation of 100,000 participants. *npj Digit. Med.* **3,** 21 (2020).

Back to the future; First remote assessment study → The HBA Study

Telephone, Telephone ASR, Home-Kiosk Query/ASR

ALZHEIMER'S DISEASE COOPERATIVE STUDY

ELSEVIER

Check for updates

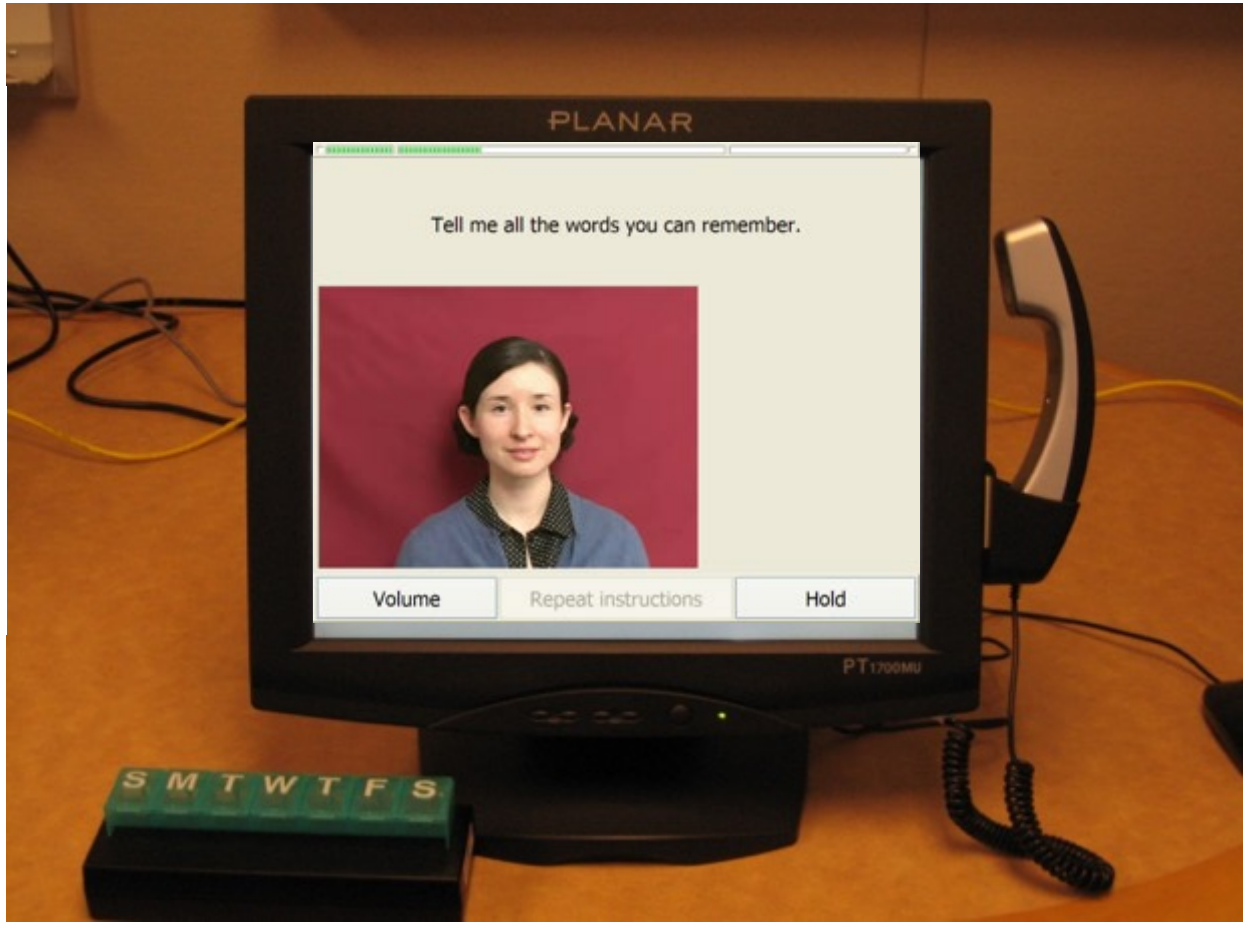
Alzheimer's & Dementia 15 (2019) 615-624

Alzheimer's & Dementia

Featured Article

A randomized clinical trial to evaluate home-based assessment of people over 75 years old

Mary Sano[a,b,*], Carolyn W. Zhu[a,b,c], Jeffrey Kaye[d], James C. Mundt[e], Tamara L. Hayes[f], Steven Ferris[g], Ronald G. Thomas[h,i], Chung-Kai Sun[j], Yanxin Jiang[j], Michael C. Donohue[j], Lon S. Schneider[k], Susan Egelko[a], Paul S. Aisen[j], Howard H. Feldman[l], for the Alzheimer Disease Cooperative Study Investigators



In-home performance (cognitive) and nonperformance–based measures (cognition, function, behavior, global clinical status, quality of life, health-related resource use)

ORCATECH
SENSING LIFE KINETICS

OREGON HEALTH & SCIENCE UNIVERSITY

Growing Number of "Cognitive APPS" (Self-Testing)

Charalambous AP, Pye A, Yeung WK, et al. **Tools for App- and Web-Based Self-Testing of Cognitive Impairment: Systematic Search and Evaluation**. *J Med Internet Res*. 2020;22(1):e14551.

- 25 met criteria for this review
- Only 7 tools had any information concerning psychometric quality
- Only 1 tool reported data on performance norms, reliability, validity, sensitivity, and specificity for the detection of cognitive impairment

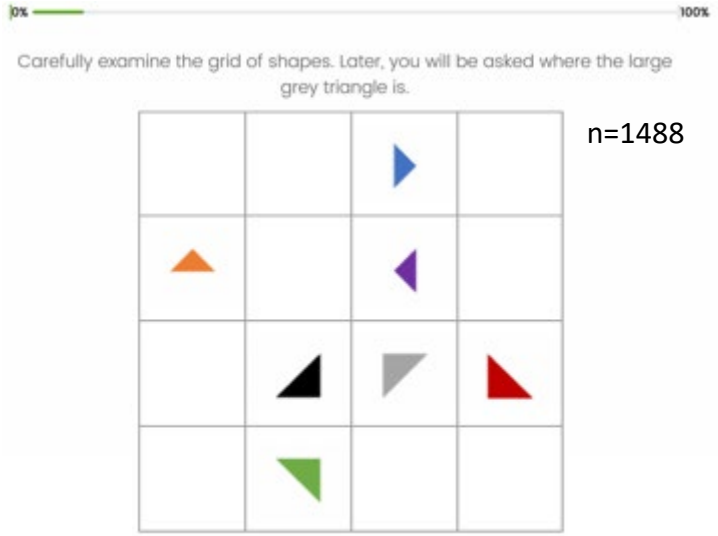
Table 2

Summary of availability of psychometric test data.

Test name	Normative data	Reliability	Validity	Sensitivity and specificity[a]
BrainTest (electronic Self-Administered Gerocognitive Examination) [21]	✓[b]	✓✓[c]	✓	✓✓
BrainCheck [23]	✓✓	✓✓	✓✓	×[d]
MemTrax–The Online Memory Screening Test (free version) [24]	×	×	×	×
MemTrax Proprietary [24]	✓✓	✓	✓	×
Self-Assessment of Cognition [25]	✓	✓	×	×
Husketest [26,27]	✓✓	×	✓✓	×
Dementia Screener [28]	×	×	×	×
DANA[e] Brain Vital [29]	✓✓	✓✓	✓✓	✓✓
DANA Modular [30]	✓✓	✓✓	✓✓	✓✓
Cogniciti [31]	✓✓	✓✓	✓✓	×
Savonix Mobile [32]	×	×	×	×
Imprint Memory Assessment [33]	×	×	×	×
Memory Quiz [34]	×	×	×	×
Dementia Test [35]	×	×	×	×
RateMyMemory [36]	×	×	×	×
Daily Mail Dementia Quiz [37]	×	×	×	×
Cognitive Function Test [38]	×	×	×	×
The Cleveland Clinic Brain Check-Up [39]	×	×	×	×
Mindcrowd [40]	×	×	×	×
MyBrainTest [41]	×	×	×	×
Memory Health Check [42]	×	×	×	×
On Memory [43]	×	×	×	×
Psychology Today Memory Test [44]	×	×	×	×
Brainlab Cognition [45]	×	×	×	×
Dementia Test–Risk Calculator of Dementia [46]	×	×	×	×
MMSE[f] [47]	×	×	×	×

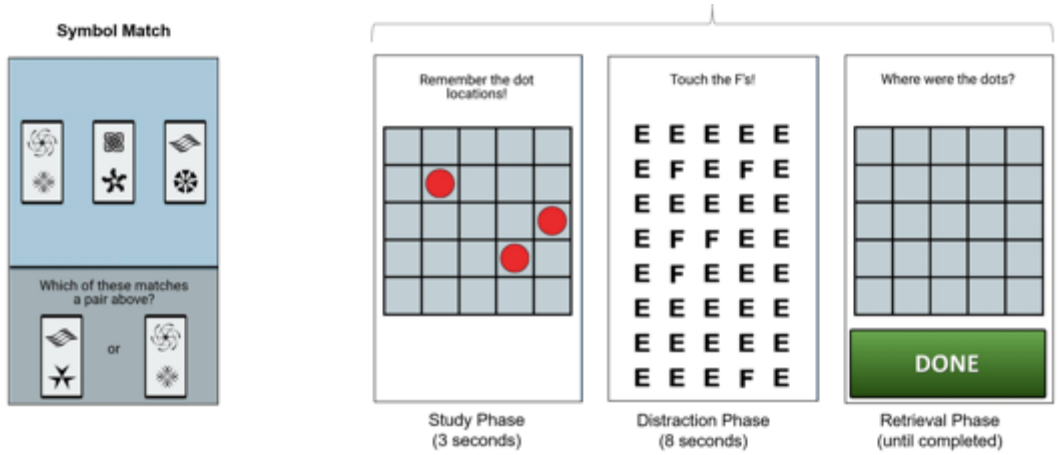
Many More in Development…

SMART Survey; Seelye et al. Univ. Minn.



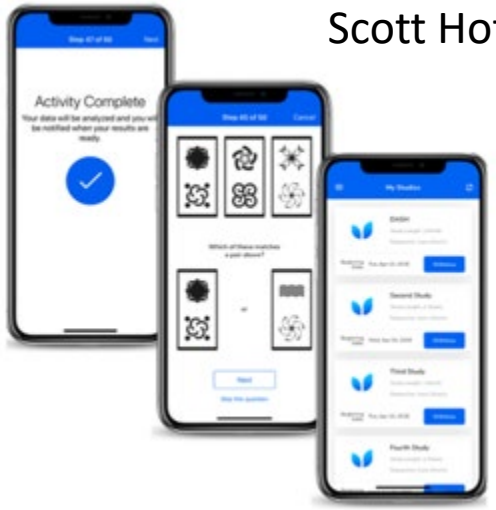
n=1488

Mobile Monitoring of Cognitive Change (M2C2, Chinchilli, Sliwinski, and Yabiku)



Mobile Toolbox for Monitoring Cognitive Function (Gershon and Nowinski, Northwestern)

MyCogHealth (Freshworks, Scott Hofer et al. Univ. Victoria)



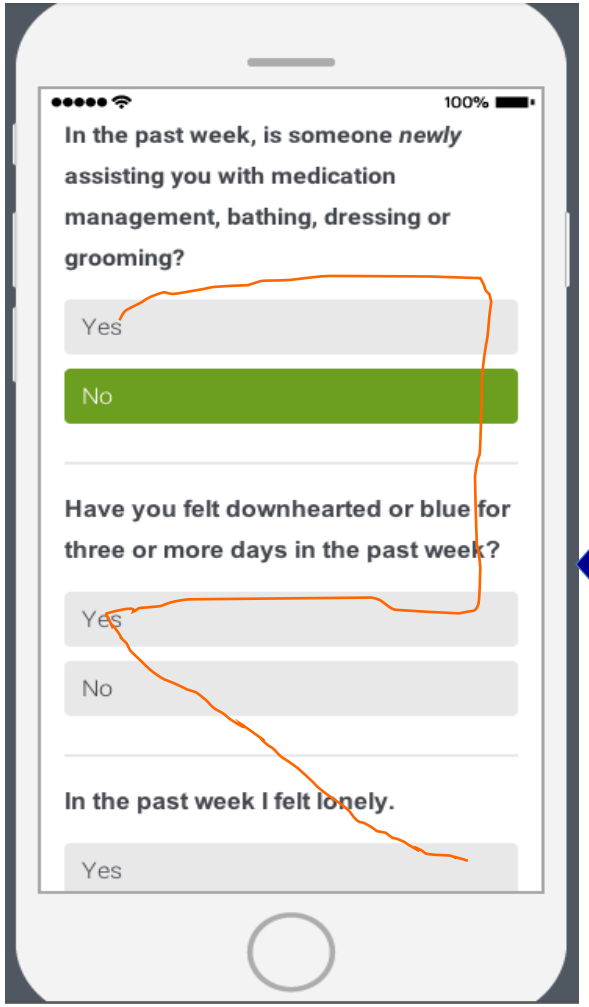
APT Webstudy
Brain Health Registry

- *Recruitment into Trials*
  - Feeds into TRC-PAD **(**Trial-Ready Cohort for the Prevention of Alzheimer's Dementia)
- Combination of cognitive screening test (Cogstate) and subjective symptoms/function questionnaire for study informant (CFI or eCog)

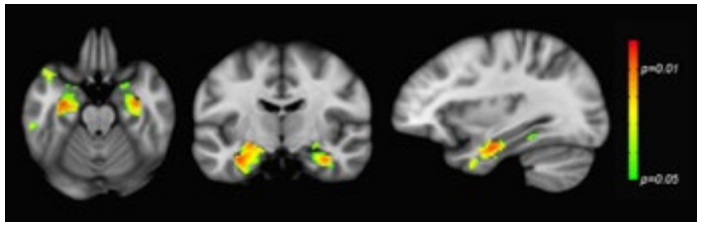
Compared to 10 years ago, has there been any change in…
Memory
1. Remembering a few shopping items without a list.
2. Remembering things that happened recently (such as recent outings, events in the news).
3. Recalling conversations a few days later.
4. Remembering where she/he has placed objects.
5. Repeating stories and/or questions.
6. Remembering the current date or day of the week.
7. Remembering he/she has already told someone something.
8. Remembering appointments, meetings, or engagements.

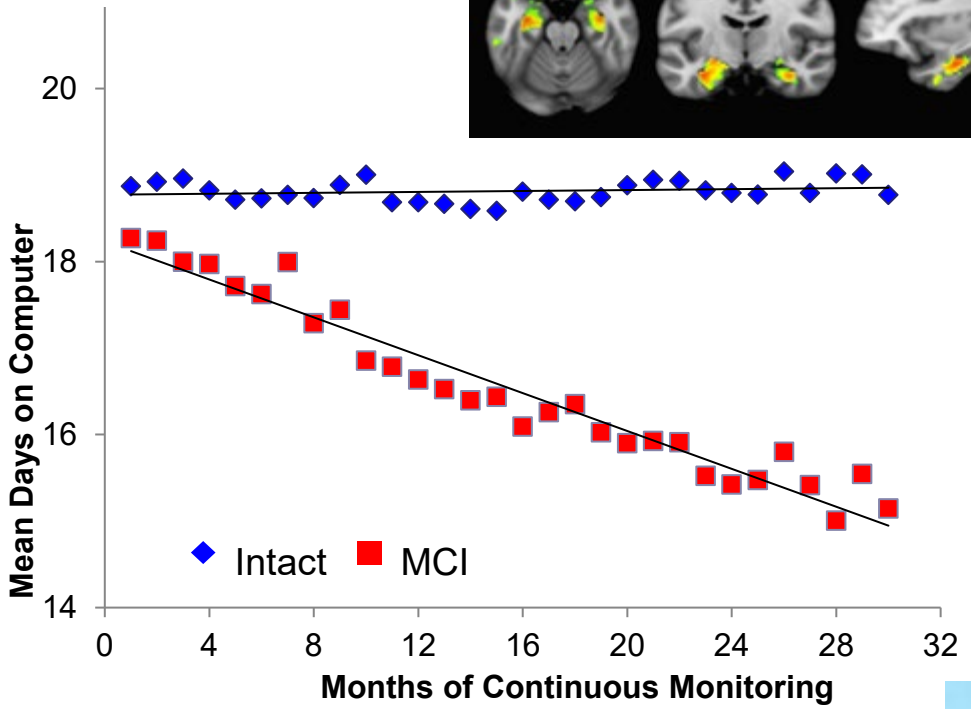
https://www.aptwebstudy.org
www.brainhealthregistry.org

Everyday Cognition *and* Behavior: Computer Use



Context is Important: Self-Report Data is Necessary





Lisa Silbert

Table 4
Associations between cognitive status and mouse movement variability derived from one week of data

	Outcome, movement curvature (IQR_K)		Outcome, time spent idling (IQR_Idle)	
Covariate	Coefficient	*P* value	Coefficient	*P* value
MCI (reference: cognitively intact group)	0.013	.008**	386.8	.04*
Age (y)	−0.001	.03*	−15.0	.31
Education (y)	0.002	.05	−12.4	.70

Abbreviations: IQR, interquartile range; MCI, mild cognitive impairment.
NOTE. *$P < .05$, **$P < .01$.

Adri Seelye

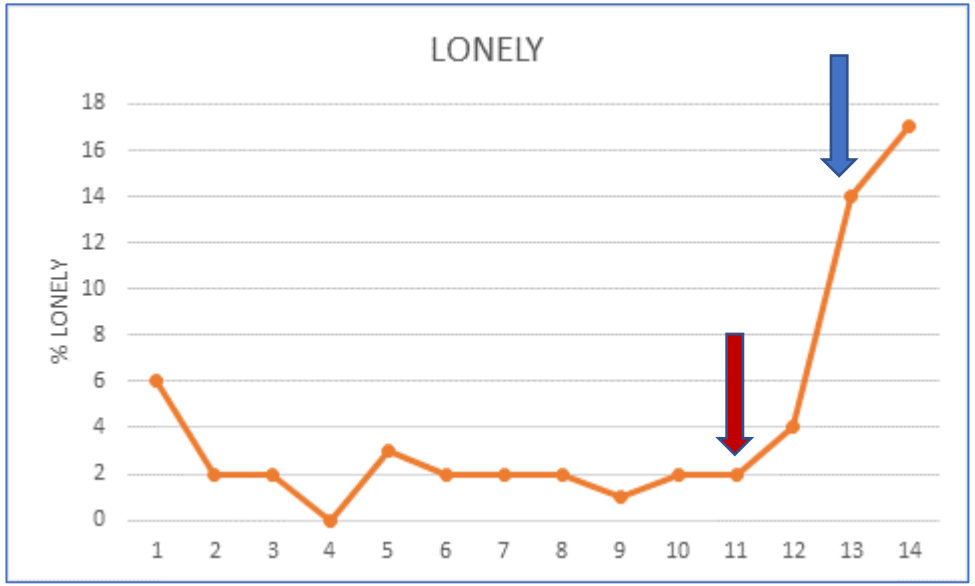
Kaye, et al. Alzheimers Dement. 2014; Silbert et al., Alzheimers Dement, 2015; Seelye et al. Alzheimers Dement.: Diagnosis, Assessment & Disease Monitoring, 2015; Seelye et al. Alzheimer's Disease & Assoc. Disorders, 2015; Seelye et al., Alzheimer & Dementia, 2018

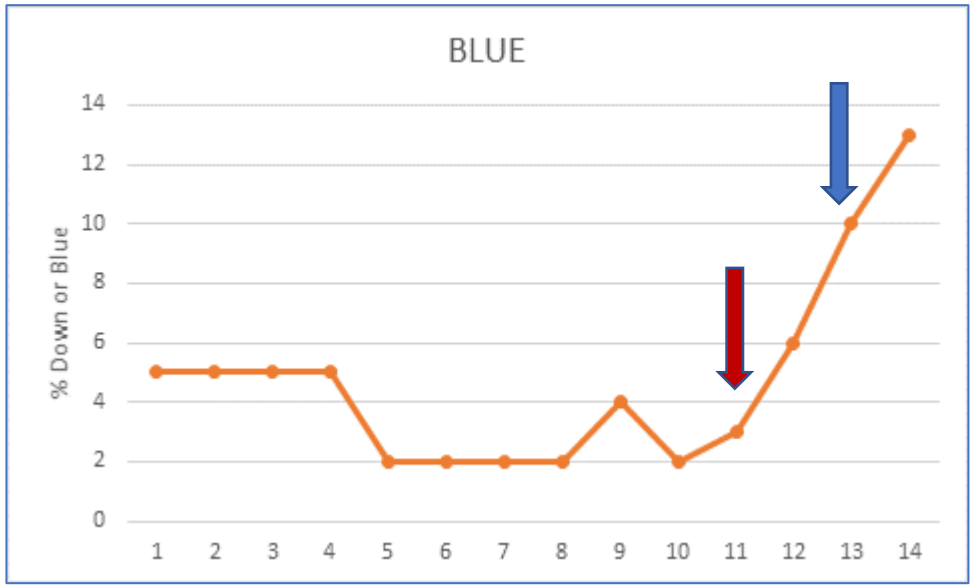
Change in Mood Among Older Adults Living Alone during the COVID-19 Pandemic

- CART Cohort: 60 older adults living alone in low income housing in Portland, Oregon
- Mean age 73; 71% women
- Data shown for 14 week period beginning January 1, 2020 – April 4, 2020 (n = 800 completed queries)

% of cohort endorsing on weekly online health and activity questionnaire :

- *Feeling downhearted or blue for three or more days in the past week.*
- *In the past week I felt lonely*





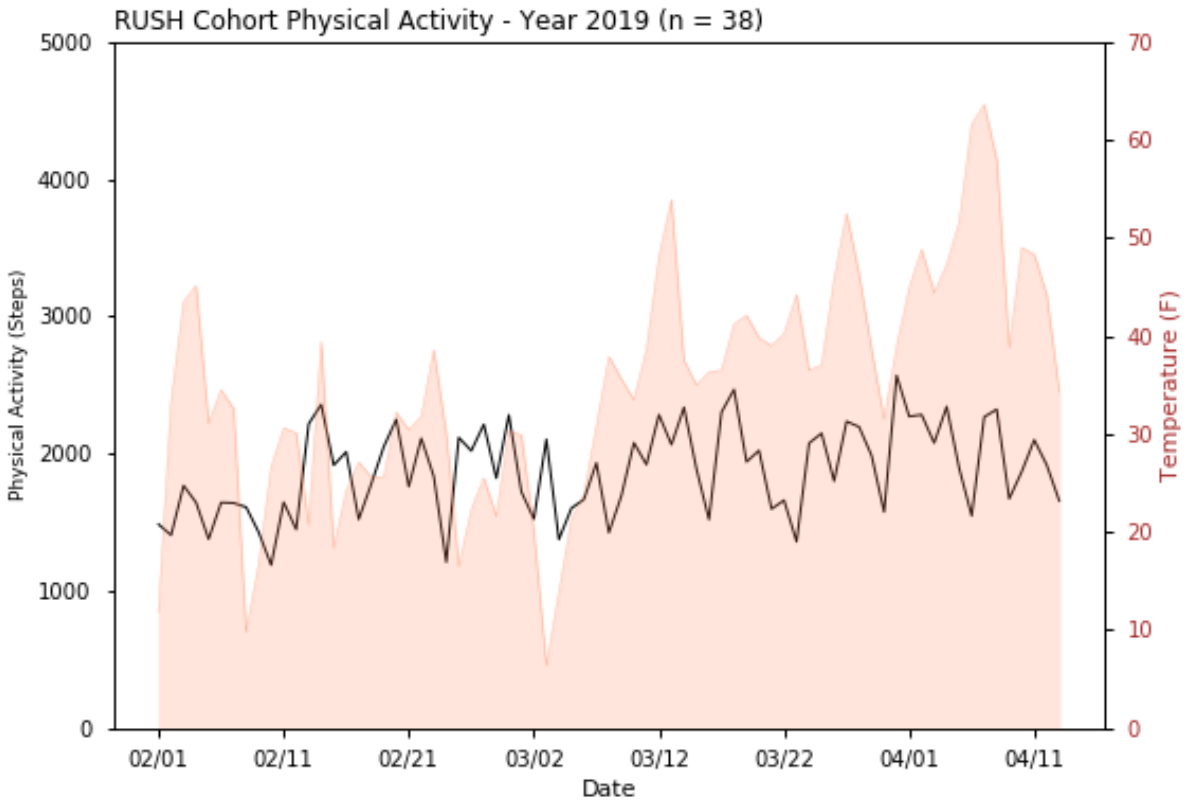
Governor announces state of Emergency: March 8

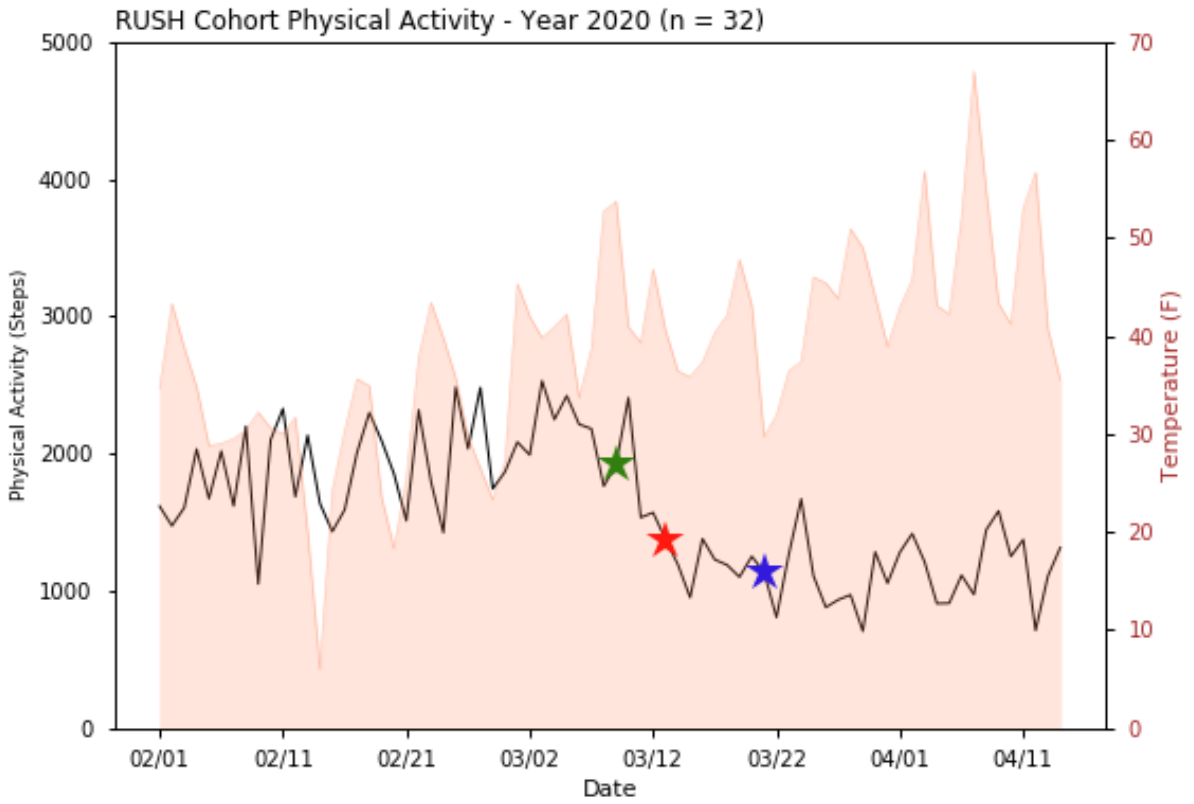
Governor's Executive Order – Stay-at-Home March 23

The CART Initiative

CART MARS Chicago cohort - Step activity

(Feb – April, 2019 and 2020) Lisa Barnes, PI





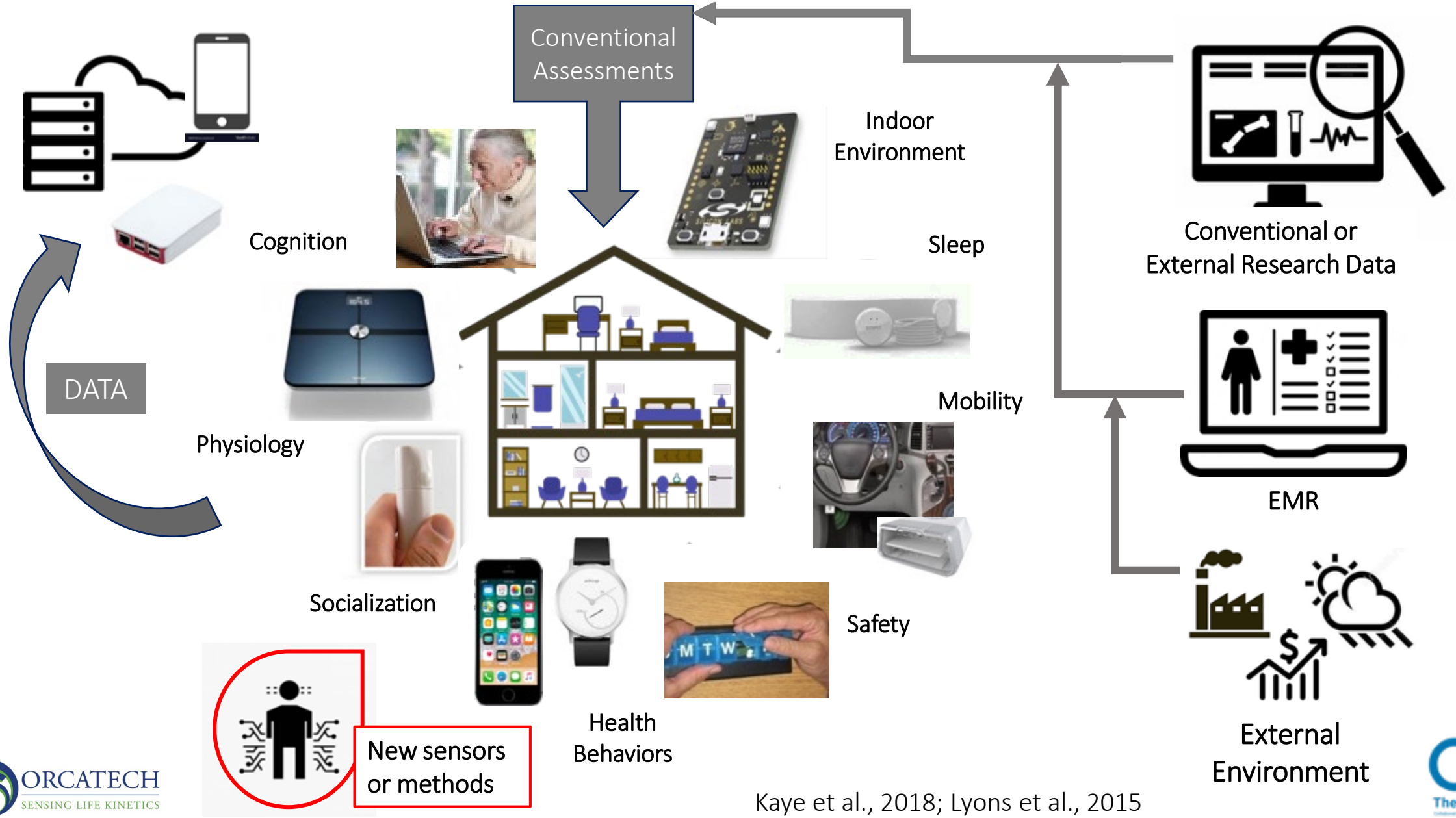
Green - Illinois state of emergency (March 9th)

Red - National emergency (March 13th)

Blue - Stay at home order (March 21st)

The CART Initiative

Ultimately there are a wide range of remotely assessable functions available



Kaye et al., 2018; Lyons et al., 2015

Summary - Recommendations

- DEFINE THE USE CASES WELL
- Use the telephone for the widest immediate capture of data
- Include technology use survey across the centers and track longitudinally
- Think more broadly than “cognitive testing”
- Research is needed: Develop multiple approaches while retaining common data standards and documentation
- Be patient
- Be well!

THANK YOU!