The National Academies of SCIENCES ENGINEERING MEDICINE

Forum on NEUROSCIENCE and NERVOUS SYSTEM DISORDERS

Harnessing Mobile Technology to Predict, Diagnose, Monitor, and Develop Treatments for Nervous System Disorders—A Workshop, *June 5-6, 2018, Keck Center of the National Academies*

Session 4: Designing with the Users

Part 2: Patient Attitudes and Preferences

'Technology Doesn't Work if People Don't Use it'

Jeffrey Kaye
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Pathways to Optimized Use of Technology

Its not about the technology –

The use case (question) & user are key

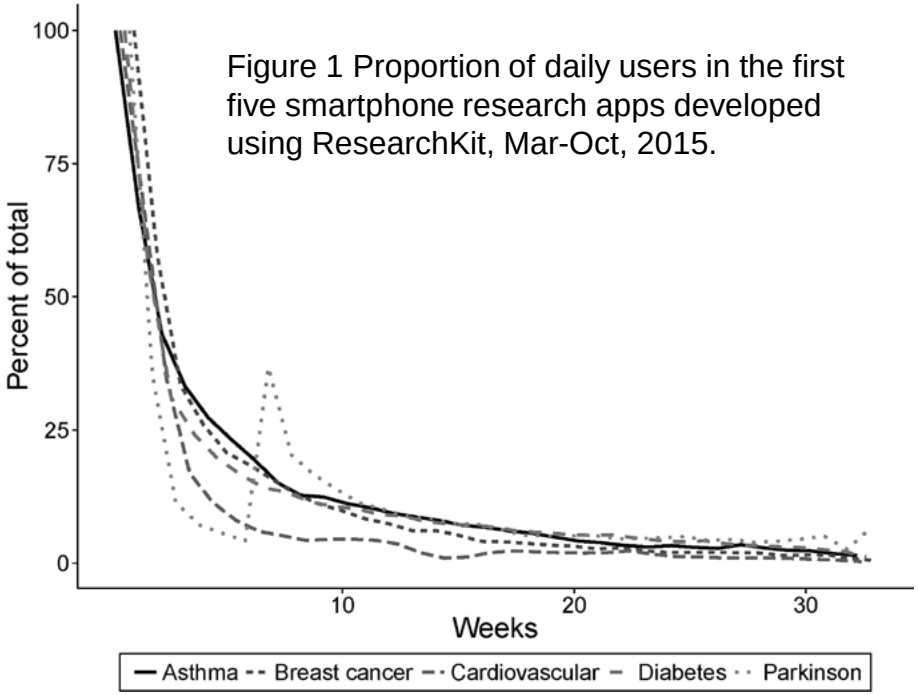

Figure 1 Proportion of daily users in the first five smartphone research apps developed using ResearchKit, Mar-Oct, 2015.

Dorsey et al. Academic Medicine, 2017;92(2):157-60.

- If you have a smartphone, everything is an app…

"Resist the law of the hammer"

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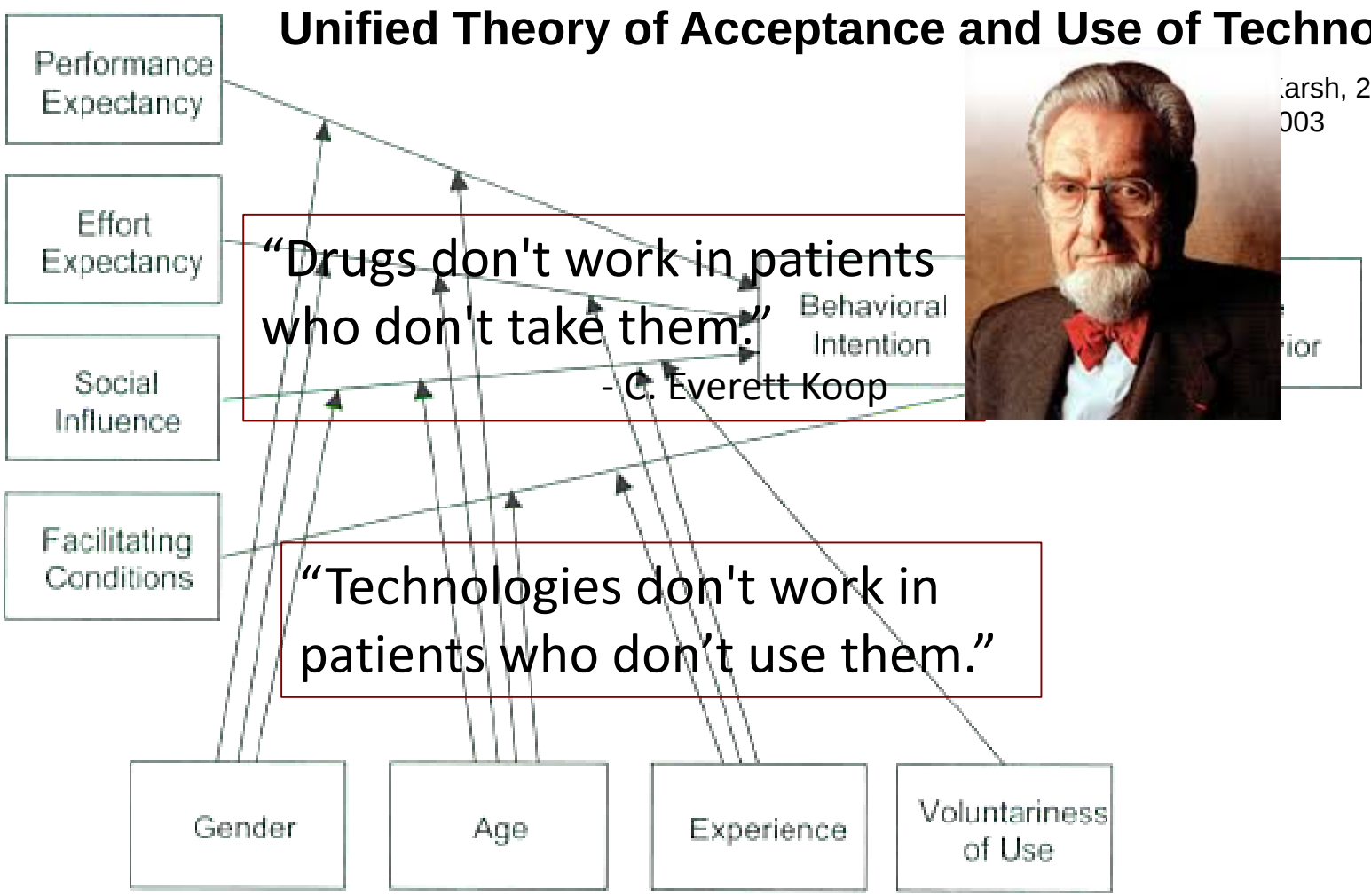
User Experience & Attitudes are Critical

Know Your 'Customers'



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Know Your 'Customers'

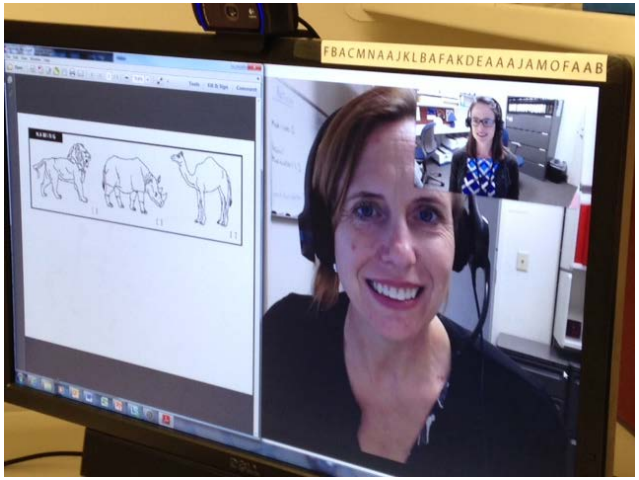
Photo Shared from a
Adult Child of a Patient

A Population
Queries for a Health System Manager

Email from Life Laboratory
Research Participant

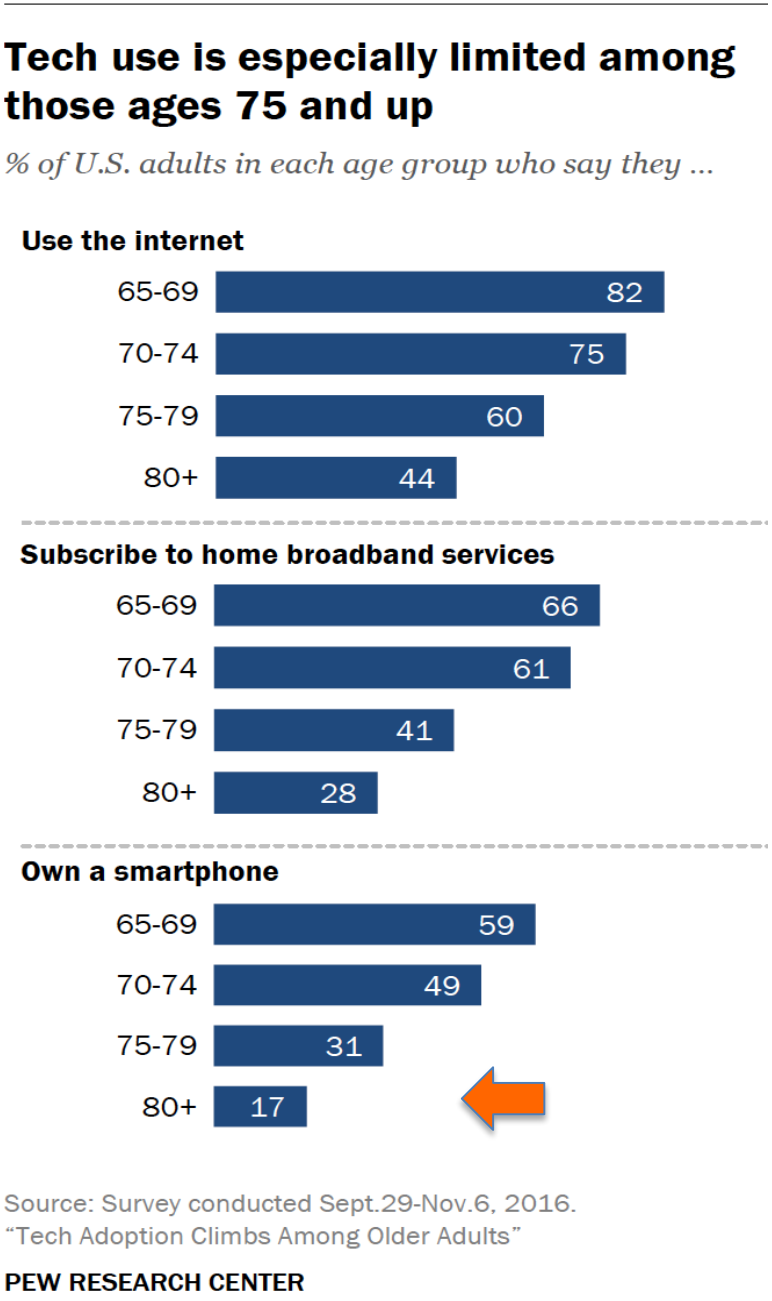
"I will be having my right arm amputated May XXth. I will probably be away from my computer for the following 10 days, so I am sorry if I do not finish next week's checklist. "

Telecare Interaction with
a Clinician



Know Your ‘Customers’

(Advanced) Age is a critical factor - especially in neurological disorders



Technology Agnostic Research Assessment System

Iron your shirt before you wear it…

Studies/Cohorts

- Life Laboratory Cohort
- Life Laboratory - BC
- AIMS Transitions
- EVALUATE - AD
- iCONECT - MI/OR
- CART - 202 Portland
- CART - VA VISN 20
- CART - MARS Chicago
- CART - PRISM Miami
- Study XYZ

Activity, Mobility, Sleep

Device - Sensor "X"

Physiology & Health

Wearable actigraphy, passive activity sensors

Physiologic Sensing: Body Composition, Pulse, Vascular Resistance, Temperature, $C0_2$

MedTracker

ORCATECH Secure Data Backend - Digital Data Repository

Secure Internet

Computer Use/EMA

Data Scientists, University Collaborations, PHARMA, Health Industry

Contact Sensors Doors Open/Close

Phone Activity/EMA

Vehicle data port

Safety

Safety & Cognition

Caregiving

Social Engagement

Cognition & Behavior

Kaye et al. Journals of Gerontology, 2011; Lyons et al. Frontiers in Aging Neuroscience, 2015; Kaye et al. JoVE, 2018

Iterative Research Process

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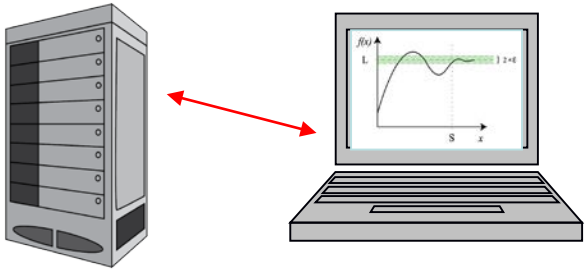
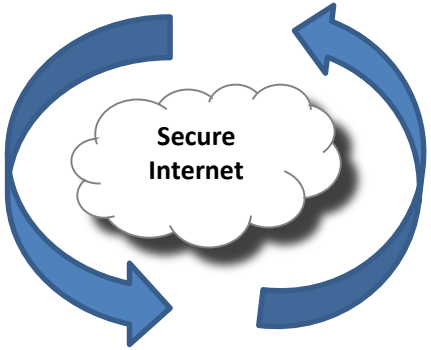
UNDERSTAND THE STAKEHOLDERS/KEY QUESTIONS
RITE (Response via Internet Technology & Experience) Cohort; Surveys, Focus Groups Participant/End-User Assessments

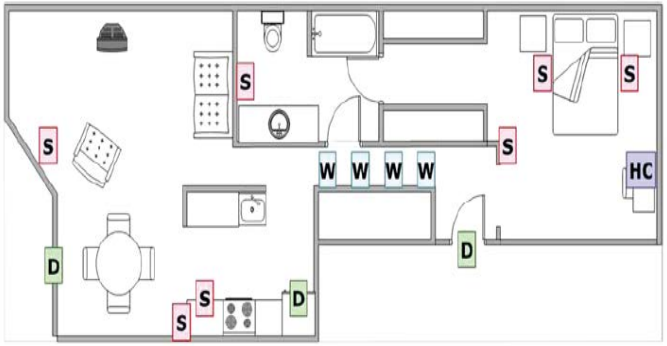
	☐ I only use a landline phone. I do *not* use a cell phone.
	☐ I use my landline often, but have a cell phone for emergencies.
	☐ I use both a landline phone and a cell phone, depending on which one is more convenient.
	☐ I use my cell phone most of the time, even at home, but I still have a landline that I use occasionally.
	☐ I don't have a landline phone, I *just* use a cell phone.

UNDERSTAND THE DATA
Data Repository, Data Aggregation, Measurement Analytics & Outcomes

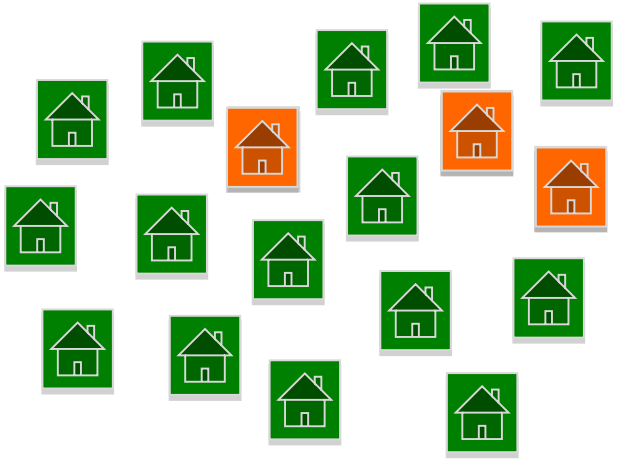




UNDERSTAND THE TECHNOLOGIES
'Smart Apartment' or Life Lab: Focused Sensor/Measurement Technology Development, Validation & Assessment



UNDERSTAND REAL WORLD USE
Life Laboratory: Large Scale Deployments / Relevant Health & Wellness Measures & Interventions in Everyday Environments

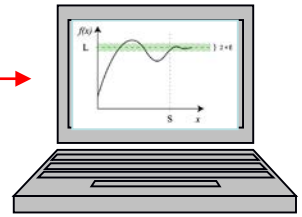


RITE COHORT: Research via Internet Technology and Experience n = 724

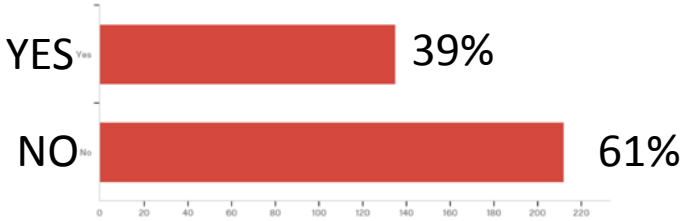
UNDERSTAND THE DATA

UNDERSTAND THE STAKEHOLDERS/KEY QUESTIONS

Robotic Pets?



Secure Internet



- Drawn from OHSU EPIC Cohort Discovery
- Record data at baseline that reflects their health and activity + Respond online to biweekly Life Lab questionnaire
- Periodic Surveys to inform research
  - Driving and Autonomous Vehicles
  - Assistive Technology for Caregiving
  - Wearables

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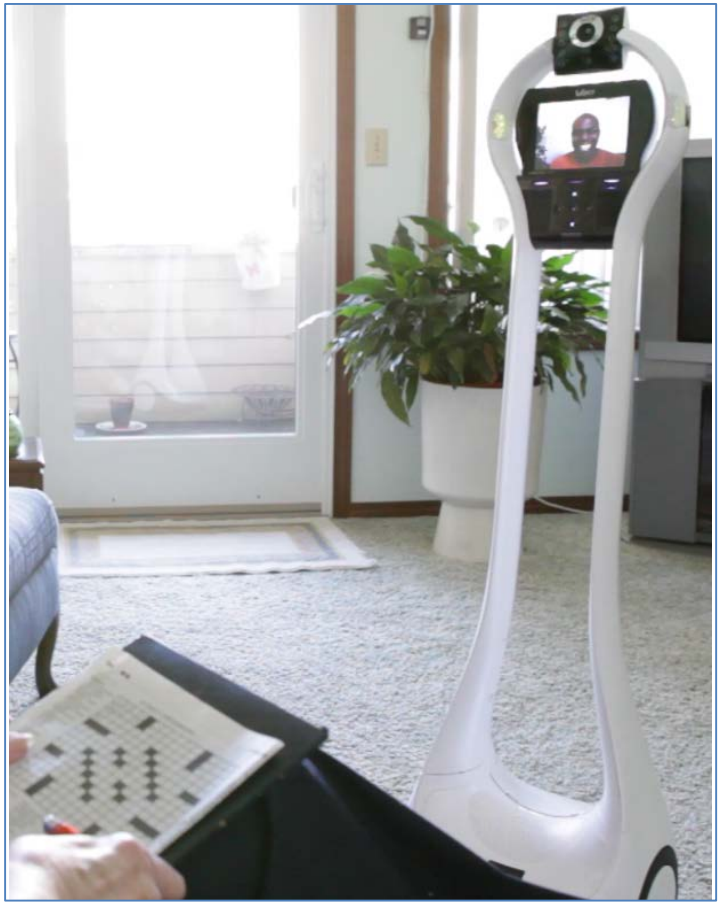
Reactions to a Remote-Controlled Video-Communication Robot in Seniors' Homes: Feasibility and Acceptance

VGO

Table 2. Example Participant Feedback
• "It was nice that my daughter didn't always have to come over."
• "Gave me a sense of safety."
• "It was like another person. I was sad to see it go."
• "It would be good for checking on a sedentary person."
• "Not sure what the purpose is supposed to be."
• "It was too complicated…overwhelming."[a]
[a]Participant who progressed to mild cognitive impairment.

Table 3. Example Remote Collateral Feedback
• "Everyone that's older should have one."
• "It's a great tool that would give the family peace of mind."
• "When I felt like checking up on him I could just log on."
• "(It would be useful) to alert health care providers of anything dangerous like elevated heart rate."



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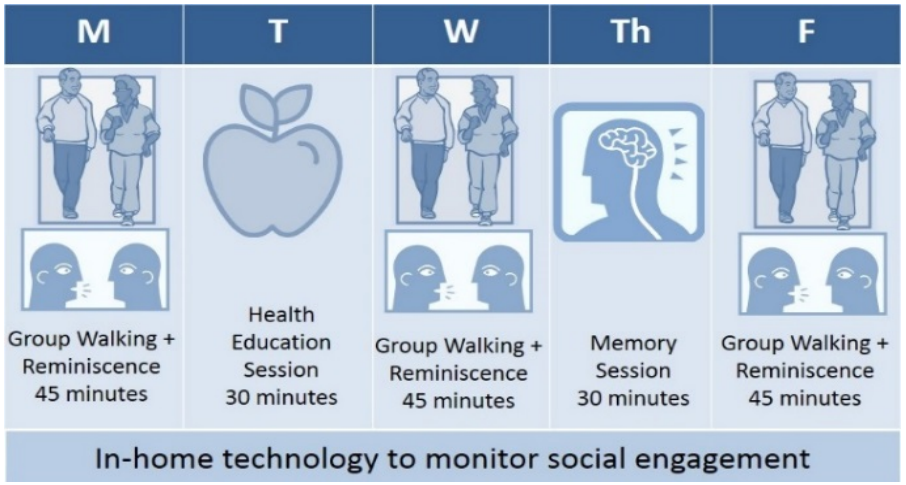
Seelye, et al. 2012 **TELEMEDICINE and e-HEALTH**

Importance of Cultural Relevance - SHARP: Sharing History through Active Reminiscence and Photo-imagery



PI: Raina Croff; NIA: P30AG008017, P30AG024978, and Alzheimer's Association

Croff R, et al. The Gerontologist, 2018.

Ambient Independence Measures for Guiding Care Transitions

NIA/NIBIB - AG042191

AIMS Summary Aims

- Based *on user-centered design*, develop a pervasive computing system tuned to identify *trends* in AIMs data predictive of relevant (for transition decisions) functional and health change. The platform will present AIMs data on a regular or as-needed basis to care teams.
- Assess the efficacy of using AIMs metrics and the data-based tool in senior community settings to improve care transition decisions via a RCT (usual care vs. AIMS informed care).

7 sites, 26 decision makers, 95 residents; 3 years follow-up

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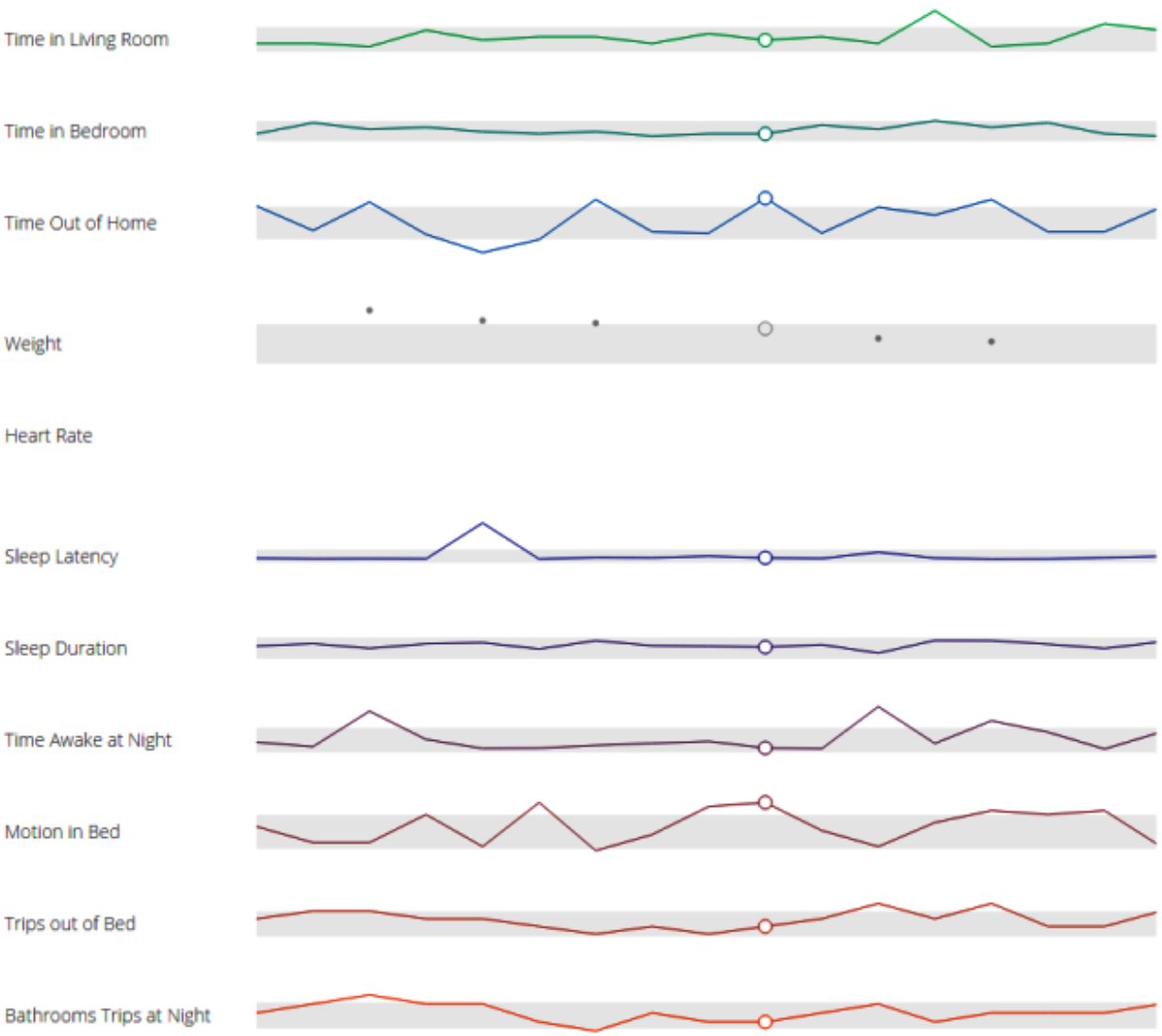
Logo for your location

View Combo Graph

May 24, 2015 | May 31, 2015 | Jun 7, 2015



	May 31, 2015 Current	Mean	Difference
Time in Living Room	4.83 min	4.94 min	-01%
Time in Bedroom	56.00 sec	1.01 sec	-05%
Time Out of Home	3.75 hr	2.15 hr	+43% !
Weight	158.16 lbs	156.65 lbs	+24%
Heart Rate	Missing	60.00	?
Sleep Latency	31.00 sec	1.04 sec	-04%
Sleep Duration	11.97 hr	11.60 hr	+03%
Time Awake at Night	10.80 min	21.45 min	-16%
Motion in Bed	12.00 #	4.68 #	+56% !
Trips out of Bed	4.00 #	4.35 #	-05%
Bathrooms Trips at Night	3.00 #	3.71 #	-12%

Viewable Period: May 18, 2015 | May 30, 2015 | Jun 10, 2015

AIMS for Guiding Care Transitions - Results

Despite user-centered design and high enthusiasm at the start of the study, and 'booster intervention' at midpoint, poor use of the dashboard over time.

Reasons (Exit interviews):

- **Not sure what to do with trend data:**

"*There is a fine line between monitoring someone's independent lives and knowing when to interfere for safety reasons… It is hard to know when to involve a care team without being too Orwellian. I would likely wait a month and then have a bit more data to take to a team meeting to assess the subtle changes collectively*."

- **Not part of Institutional System (Optional / Voluntary Use)**
  - Separate system from their facility's system
  - Not clear who should take the lead on the data
  - Just trying to keep the toilets working

Testing Acceptance for Interventions:
The "Social Engagement Study" (H. Dodge, PI)
RCT Pilot to Test Increasing Social Interaction in MCI Using Home-based Technologies

- 6 week RCT of daily 30 min video chats using automated Internet connected personal computers with a webcam vs. weekly brief phone interview
- N = 86; 80.5 ± 7 yrs; MCI & Normal Cognition
- **89% of all possible sessions completed; Exceptional adherence – *no drop-out***
- MCI participants > proportion of words (2985 vs. 2423) per total number of words during the conversation sessions (controlling for age, gender, interviewer and time of assessment; p=0.03).

Dodge et al. Alzheimer's & Dementia: TRCI, 2015
Dodge et al., Current Alzheimer's Disease, 2015

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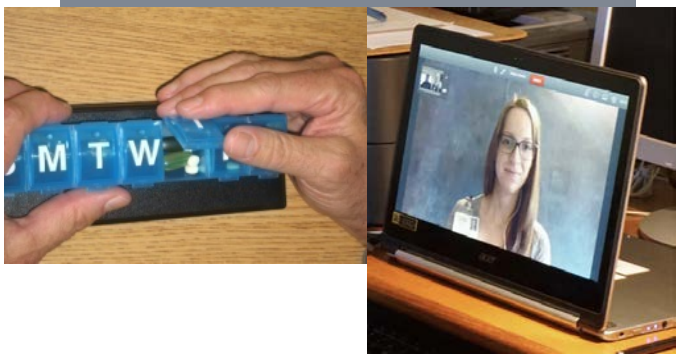
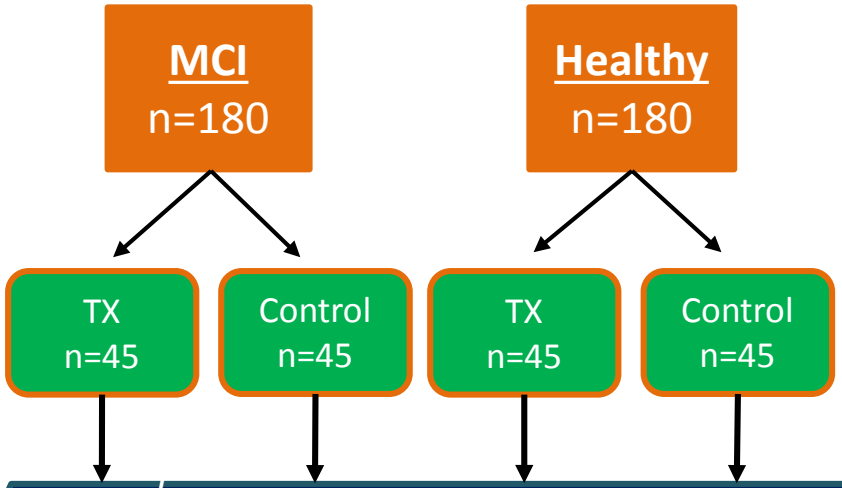
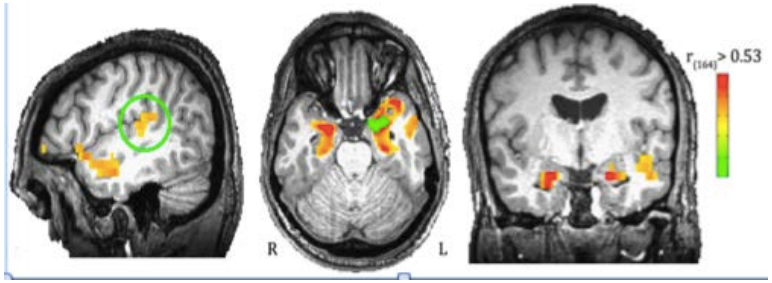
I-CONECT: *Internet-based Conversational Engagement Clinical Trials* (PI: Dodge NIA R01AG051628; NIA R01AG056102)



- Isolated 80+ yrs
- 50% African American





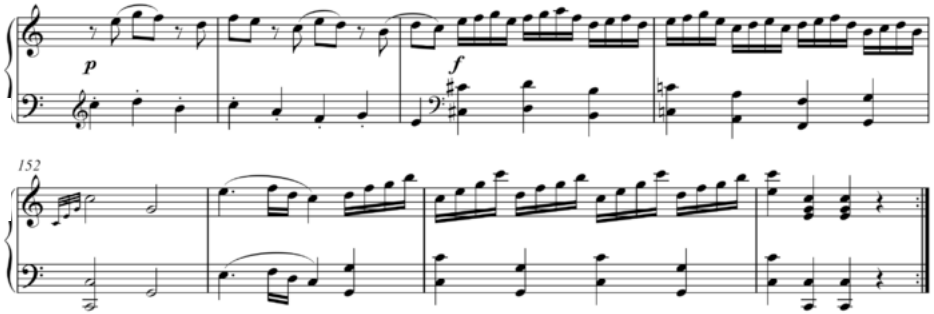
X: Video Chat, 4 times/week: 6 months, 2 times/ week: 6 months
Control: 1/wk phone check. Novel Outcome Measures: MedTracker memory, Conversational Speech & Language Quantification; vMRI, DTI, fMRI

CART - *Collaborative Aging Research Using Technology Initiative* www.carthome.org

National Institutes of Health

Department of Veterans Affairs

- Interagency U2C (U2CAG054397) with NIH (NIA, NIBIB, NCI, NINDS, NINR, NC[illegible] to address



CODA

Collaborate? Please contact us:

www.carthome.org kaye@ohsu.edu

sharing.

- Research Team: PI, Jeffrey Kaye, ORCATECH/Oregon Health & Science University; Nina Silverberg, NIA; Collaborators: Intel, U. Miami, Cornell, Rush, OSU, U. Penn, VA VISN 20

Thank you!

"It's a special hearing aid. It filters out criticism and amplifies compliments."

kaye@ohsu.edu
www.carthome.org
www.orcatech.org

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Do Perceptions Change with Time?

Willingness of older adults to share data and privacy concerns after exposure to unobtrusive in-home monitoring

Comparison Between Survey Response at Baseline and One Year Follow-up among Cognitively Intact and MCI participants

	Cognitively Intact		MCI	
	N=92		*N=27*	
Privacy and Security Concerns	**Baseline**	**1 Year**	**Baseline**	**1 Year**
I am concerned information could be given to people/organizations that do not have a right to it.	61%	85%[c]	44%	76%
I am concerned information could be given to people/organizations that would use it in a way that would harm me.	65%	93%[d]	44%	76%[e]
I am concerned about privacy in relation to in-home activity monitoring.	44%	52%	32%	52%
I am concerned about privacy in relation to monitoring of computer use.	41%	48%	29%	54%

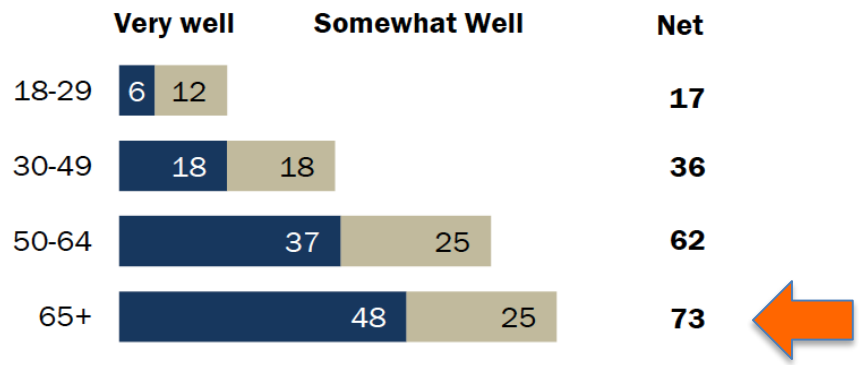
Boise et al. Gerontechnology . 2013 ; 11(3): 428–435.

Know Your 'Customers'

Age is a critical factor (especially in neurologic disease)

Most seniors say they need help using new electronic devices

% of U.S. adults who say the statement, 'When I get a new electronic device, I usually need someone else to set it up or show me how to use it,' describes them very or somewhat well, by age

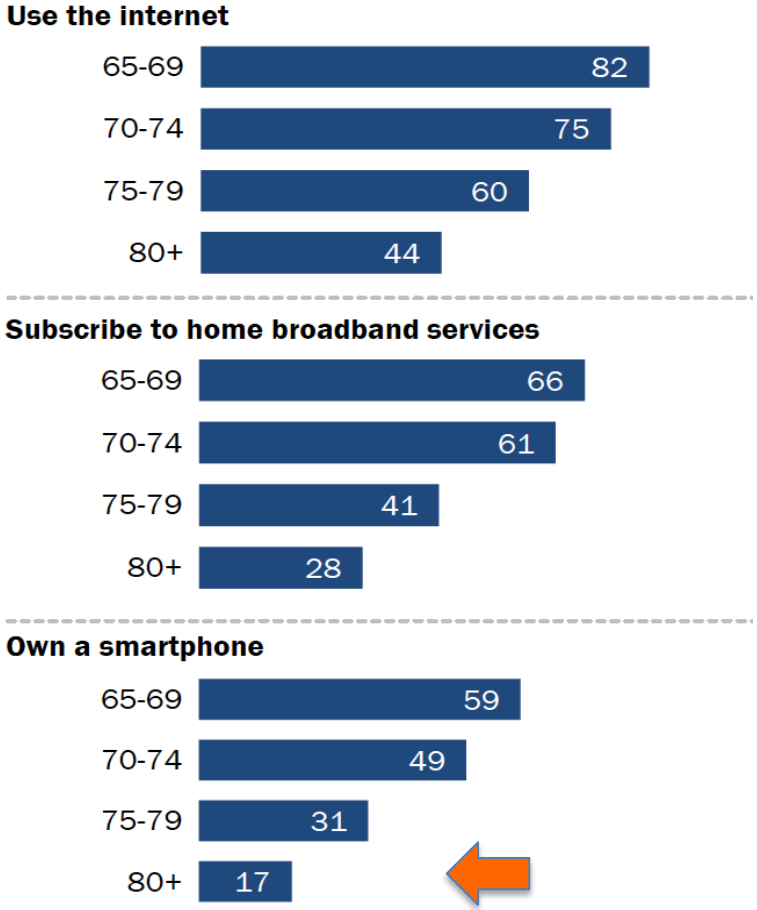


Note: NET category calculated prior to rounding.
Source: Survey conducted Oct. 13- Nov. 15, 2015.
"Tech Adoption Climbs Among Older Adults"

PEW RESEARCH CENTER

Tech use is especially limited among those ages 75 and up

% of U.S. adults in each age group who say they ...



Source: Survey conducted Sept.29-Nov.6, 2016.
"Tech Adoption Climbs Among Older Adults"

PEW RESEARCH CENTER

AIMS for Guiding Care Transitions

Seven Retirement Communities / 26 Decision Makers

Directors, nurses, social workers, resident care coordinators); ages 21-66 (mean = 40 yrs); employed at facility mean = 10 yrs; education- high school to master's (68% ≥ college)

Care staff focus groups and surveys addressing:

- If the data showed information that was meaningful to them;
- If they believed residents would be willing to have that type of data shared with the transition teams;
- If anybody, it might be helpful to share the data with;
- If there were other types of data they would like to see;
- How, and how often, data should be presented for their decision making.

Focus groups held in two waves:

1st round - three sites; 2nd round, initial feedback incorporated into the online dashboard for additional input. Dashboard designer present at all focus groups

Review of Evidence (Example) Monitoring Devices

digital biomarkers

Digit Biomark 2018;2:11–30
DOI: 10.1159/000486347
Received: August 18, 2017
Accepted: December 13, 2017
Published online: January 31, 2018

Review Article

Use of Mobile Devices to Measure Outcomes in Clinical Research, 2010–2016: A Systematic Literature Review

Brian Perry[a, b] Will Herrington[c] Jennifer C. Goldsack[b, d]
Cheryl A. Grandinetti[e] Kaveeta P. Vasisht[e] Martin J. Landray[c]
Lauren Bataille[f] Robert A. DiCicco[g] Corey Bradley[h] Ashish Narayan[i]
Elektra J. Papadopoulos[e] Nirav Sheth[j] Ken Skodacek[k] Komathi Stem[l]
Theresa V. Strong[m] Marc K. Walton[n] Amy Corneli[a, b]

ence monitors, and (5) location monitors; inertial sensors/accelerometers were most common (reported in 86% of the publications). Among the variety of mobile outcomes, various assessments of physical activity were most common (reported in 74% of the publications). Other mobile outcomes included assessments of sleep, mobility, and pill adherence, as well as biomarkers assessed using a mobile device, including cardiac measures, glucose, gastric reflux, respiratory measures, and intensity of head-related injury. ***Conclusion:*** Mobile devices are being widely used in clinical research to assess outcomes, although their use in interventional research to assess therapeutic effectiveness is limited. For mobile devices to be used more frequently in pivotal interventional research – such as trials informing regulatory decision-making – more focus should be placed on: (1) consolidating the evidence supporting the clinical meaningfulness of specific mobile outcomes, and (2) standardizing the use of mobile devices in clinical research to measure specific mobile outcomes (e.g., data capture frequencies, placement of device). To that aim, this manuscript offers a broad overview of the various mobile outcome assessments currently used in observational and interventional research, and categorizes and consolidates this information for researchers interested in using mobile devices to assess outcomes in interventional research.

Evidence... (systematic reviews)

Lui L, Strouliab E, Nikolaidisc I, Miguel-Cruza,d A, Rincona AR. Smart homes and home health monitoring technologies for older adults: A systematic review. International Journal of Medical Informatics. 2016;91:44-59

D'Onofrio G, Sancarlo D, Ricciardi F, Panza F, Seripa D, Cavallo F, Giuliani F, Greco A. Information and communication technologies for the activities of daily living in older patients with dementia: A systematic review. Journal of Alzheimer's Disease. 2017 Jan 1;57(3):927-35.

Vegesna A, Tran M, Angelassio M, Arcona S. Remote Patient Monitoring via Non-Invasive Digital Technologies: A Systematic Review. Telemed J E Health. 2017 Jan;23(1):3-17

Ienca M, Fabrice J, Elger B, Caon M, Pappagallo AS, Kressig RW, Wangmo T. Intelligent Assistive Technology for Alzheimer's Disease and Other Dementias: A Systematic Review. Journal of Alzheimer's Disease. 2017 Jan 1;56(4):1301-40.

Van der Roest HG, Wenborn J, Pastink C, Dröes RM, Orrell M. Assistive technology for memory support in dementia. Cochrane Database of Systematic Reviews 2017, Issue 6. Art. No.: CD009627.DOI: 10.1002/14651858.CD009627.pub2.

Evidence...

Davis MM, Freeman M, Kaye J, Vuckovic N, Buckley DI. A systematic review of clinician and staff views on the acceptability of incorporating remote monitoring technology into primary care. Telemedicine and e-Health. 2014 May 1;20(5):428-38.

Pillai JA, Bonner-Jackson A. Review of information and communication technology devices for monitoring functional and cognitive decline in Alzheimer. Journal of Healthcare Engineering. 2015;6(1):71-84

Peetoom KK, Lexis MA, Joore M, Dirksen CD, De Witte LP. Literature review on monitoring technologies and their outcomes in independently living elderly people. Disability and Rehabilitation: Assistive Technology. 2015 Jul 4;10(4):271-94.

Yusif S, Soar J, Hafeez-Baig A. Older people, assistive technologies, and the barriers to adoption: A systematic review. International journal of medical informatics. 2016 Oct 1;94:112-6.

Lui L, Strouliab E, Nikolaidisc I, Miguel-Cruza,d A, Rincona AR. Smart homes and home health monitoring technologies for older adults: A systematic review. International Journal of Medical Informatics. 2016;91:44-59

Summary of Evidence & Gaps

- The technologies used are wide-ranging (passive sensors, wearables, apps, integrated multi-domain systems...), and used in many types of assessments and interventions;
- Overall, few studies relative to other research areas: this is still a small field;
- Standardization gaps: variability in the devices or technologies used (hardware/software), and limits in specification of the systems deployed and the analytic algorithms applied;
- More research needed on usability;
- Various benefits may be reported but mainly based on low-quality studies (small sample sizes, short study periods, biased designs, non-diverse populations);
- Barriers to deployment of technologies in care are prevalent (ease of use, research expertise, costs, *and lack of evidence of efficacy or effectiveness*).

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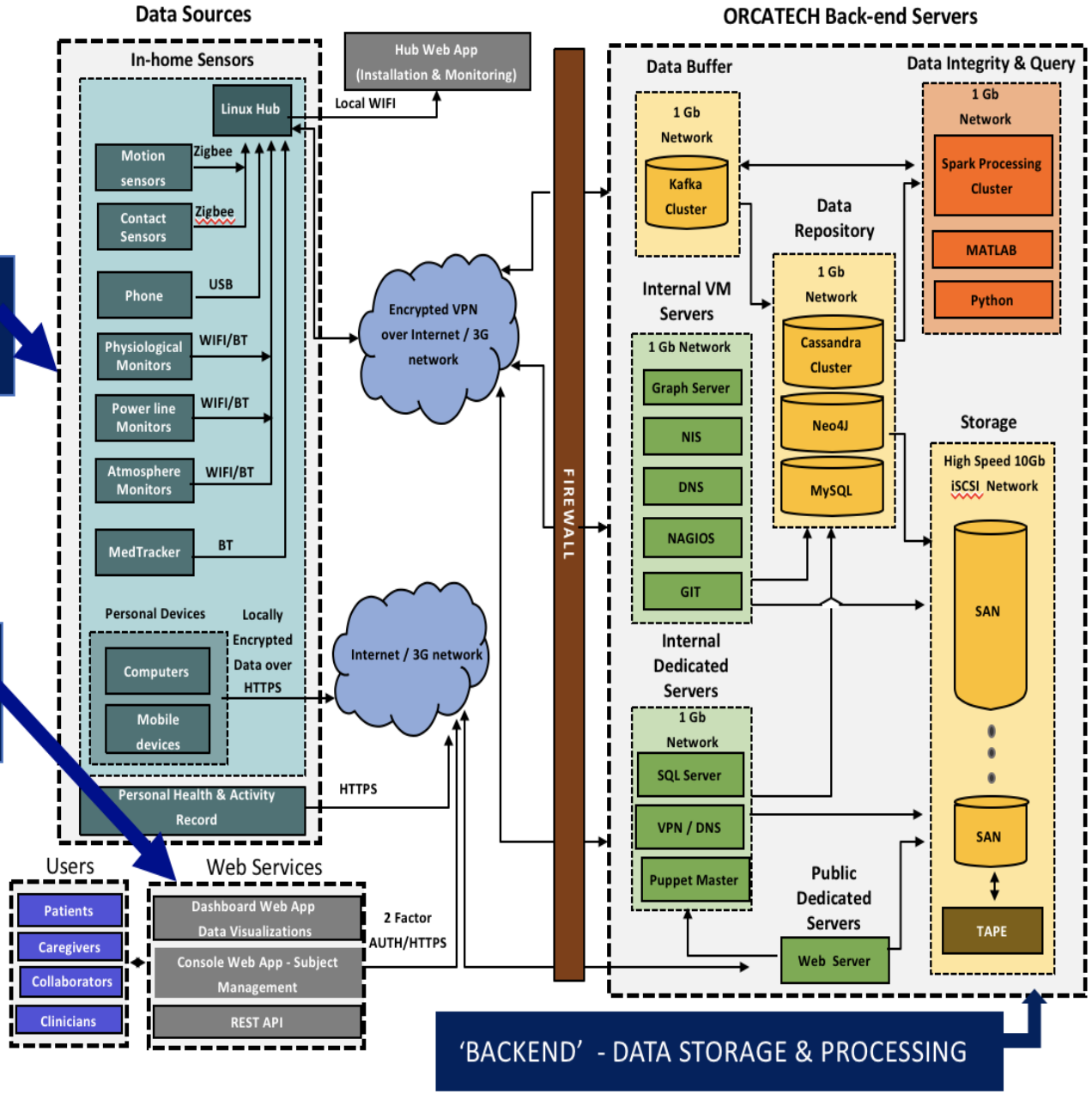
SENSORS OR DEVICES IN HOME OR COMMUNITY

WEB SERVICES:
- APPS
- PROJECT MGT.



'BACKEND' - DATA STORAGE & PROCESSING

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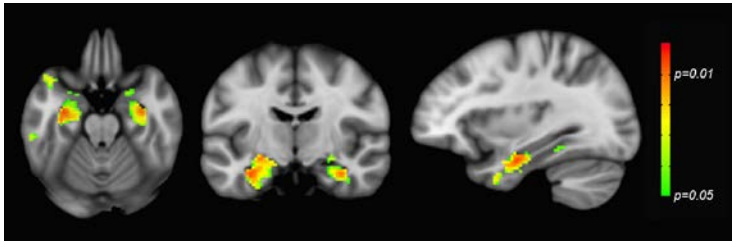
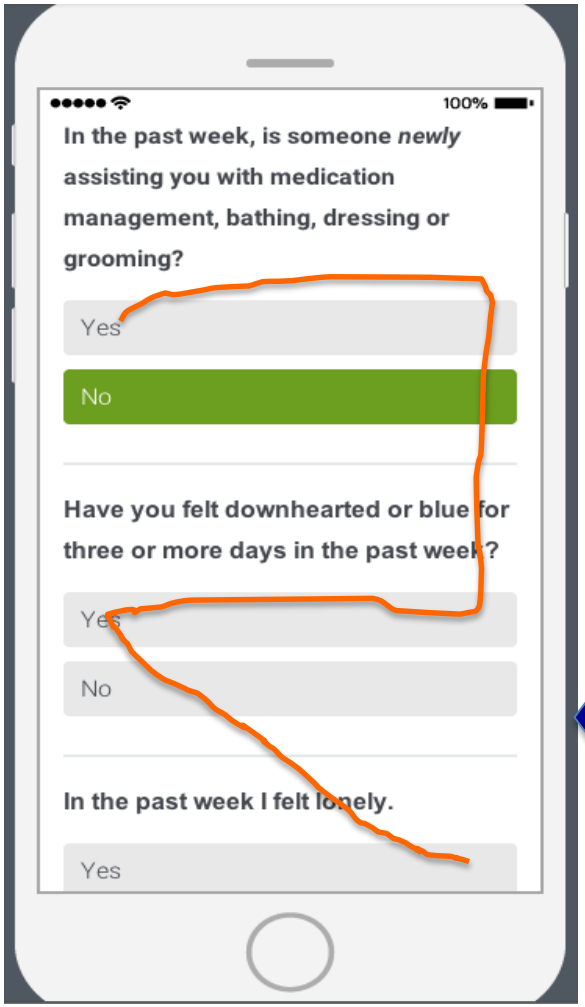
Cognition, Behavior, Motor Function: Computer Use





Some Self-Report Data is Necessary

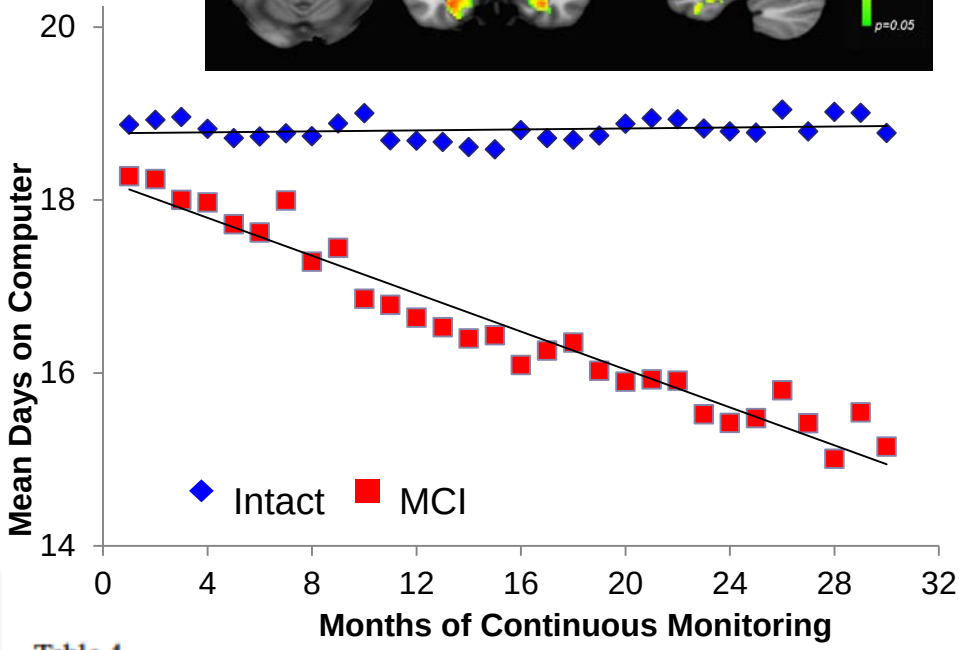


Table 4
Associations between cognitive status and mouse movement variability derived from one week of data

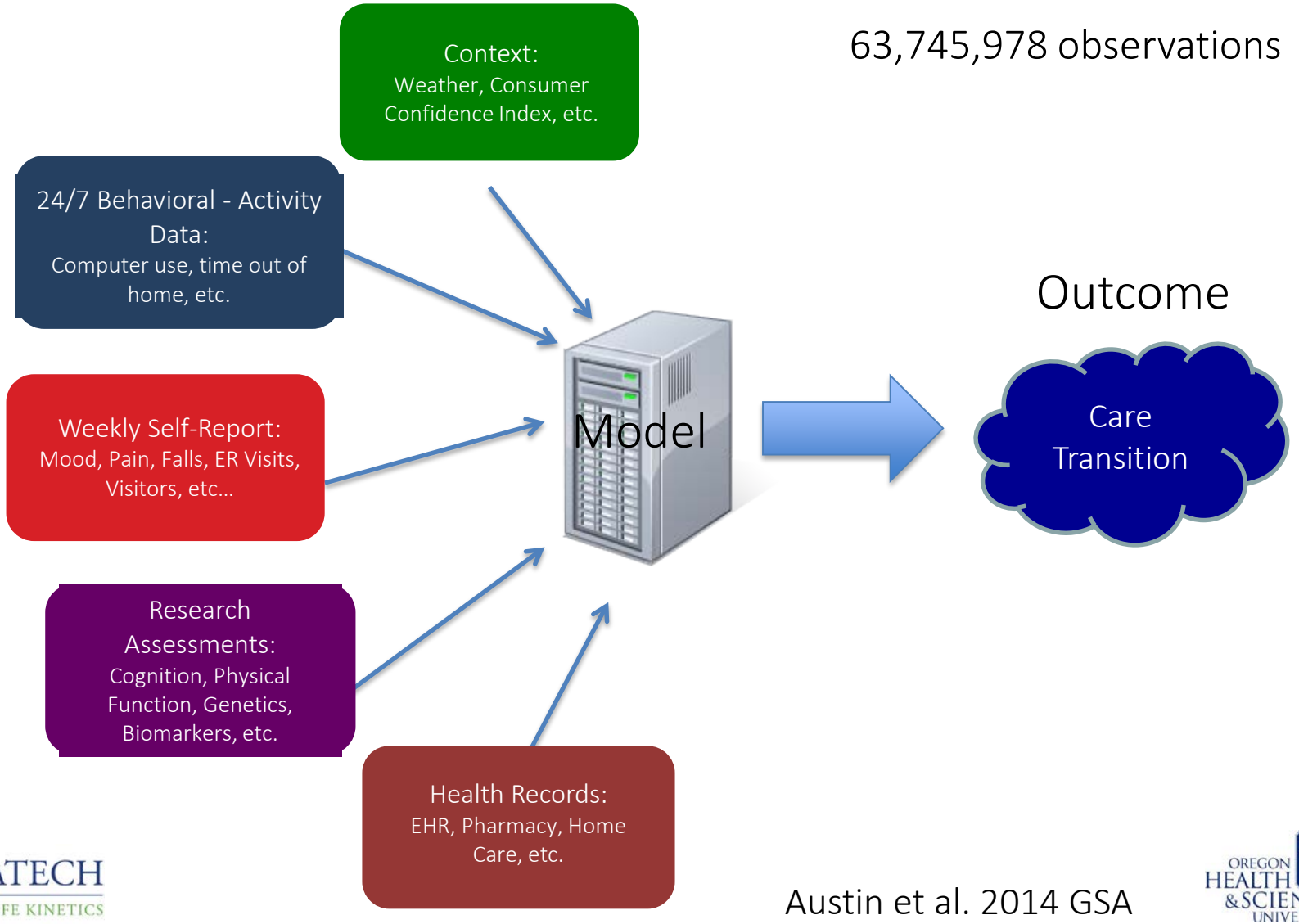
	Outcome, movement curvature (IQR_K)		Outcome, time spent idling (IQR_Idle)	
Covariate	Coefficient	*P* value	Coefficient	*P* value
MCI (reference: cognitively intact group)	0.013	.008**	386.8	.04*
Age (y)	−0.001	.03*	−15.0	.31
Education (y)	0.002	.05	−12.4	.70

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

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

AIMS to Delay Care Transitions: High dimensional *multi-domain* data fusion model for predicting care transitions

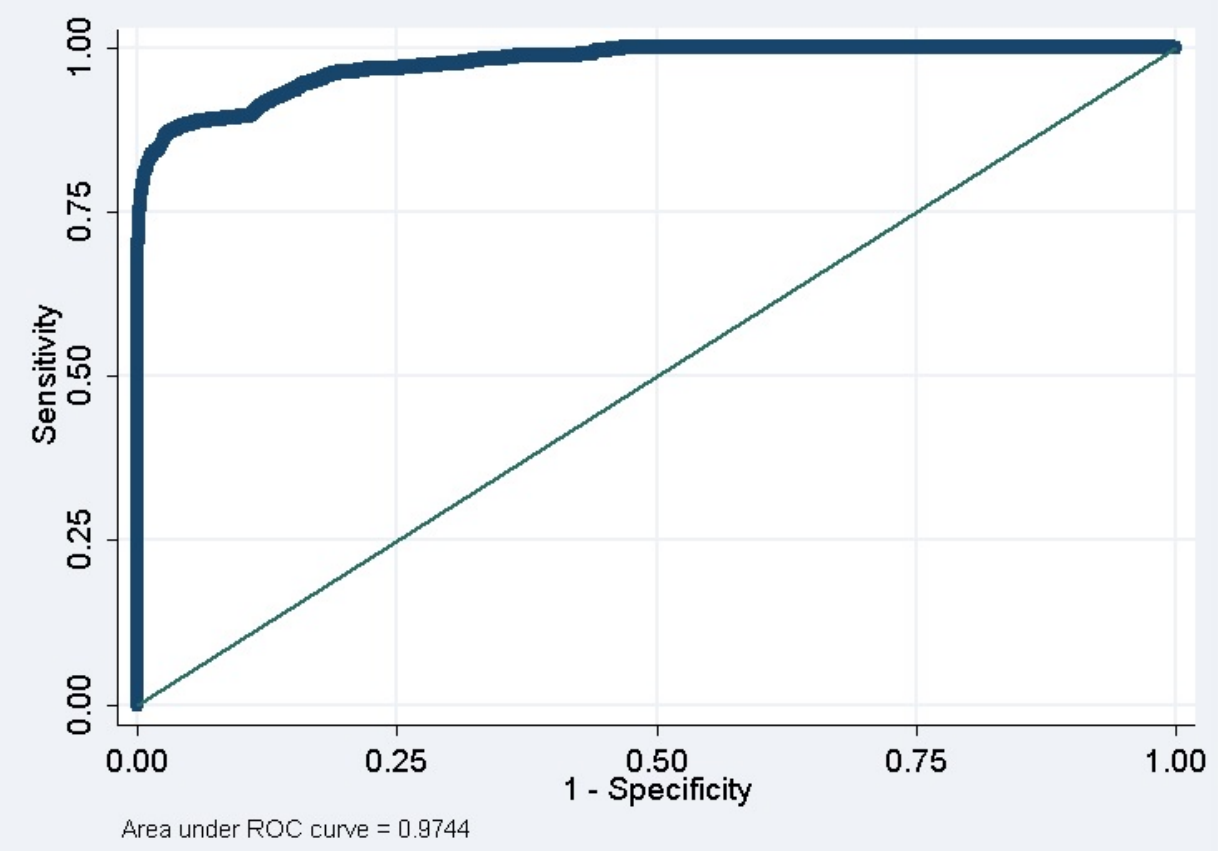
63,745,978 observations



Austin et al. 2014 GSA

Predicting Care Transitions: Sensitivity Analysis

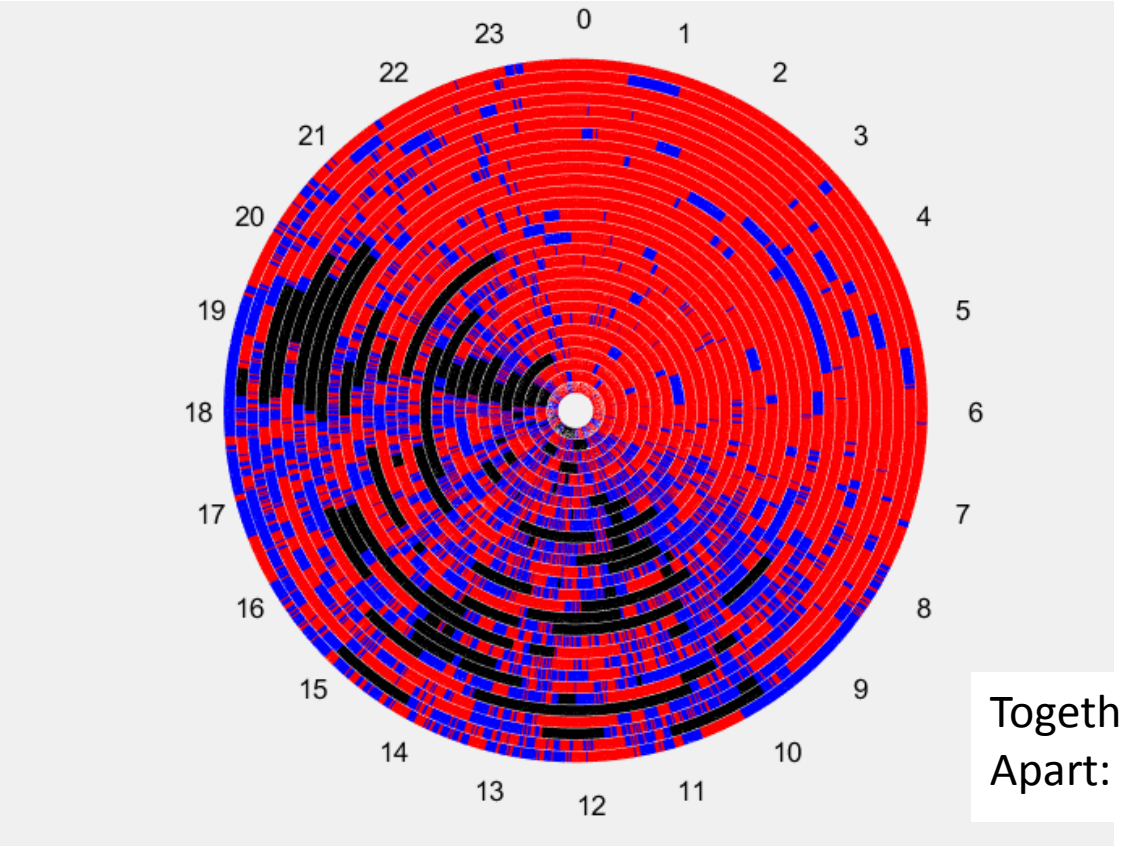
- Likelihood of a person transitioning within next six months – ROC AUC under curve= 0.974



Austin et al. 2014 GSA

EVALUATE – AD

Couples & Caregiving Analysis: Time spent together



Together

Separate

Out of Home

Together: 1285 minutes (21.4 hrs/day)
Apart: 155 minutes (2.6 hrs/day)

ORCATECH
SENSING LIFE KINETICS

Reynolds et al., 2017 unpublished
Thomas et al., AAIC 2017; AAN, 2018

OREGON HEALTH & SCIENCE UNIVERSITY
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Cognition: Online (Computer/Internet-based) Testing

Survey for Memory, Attention, and Response Time (SMART)

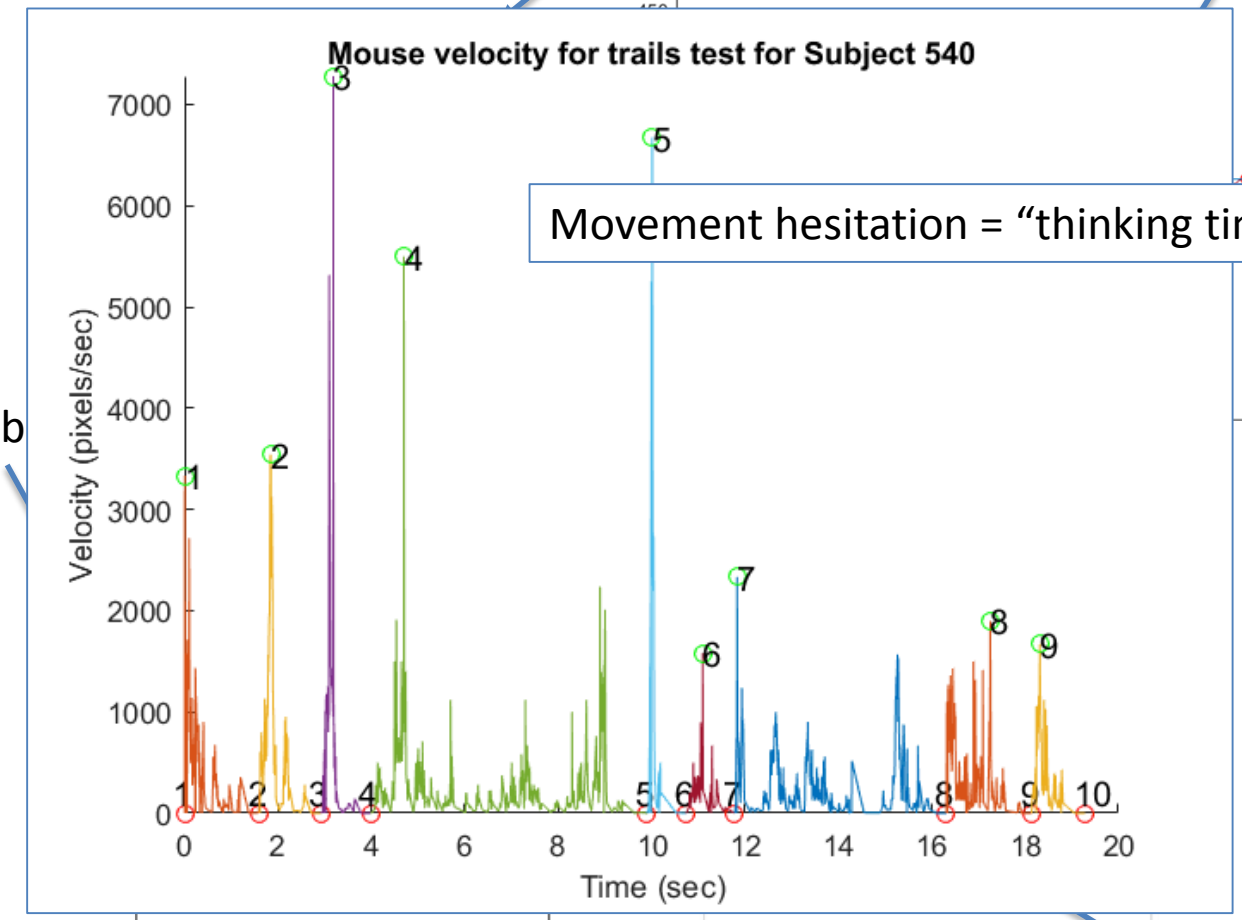
‘Face-valid’ cognitive tasks

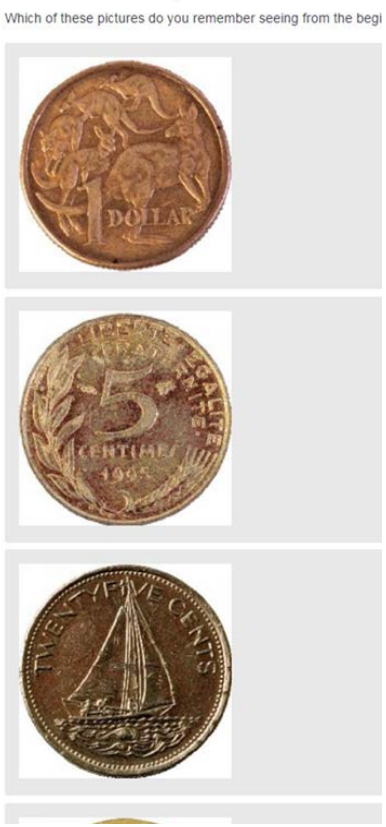
Mouse/touchscreen movements

Image Memory

Prob

Typing speed





Seelye, AAIC 2017