Clinical Core: The Backbone of the Adult Changes in Thought Study

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Kaiser Permanente Washington Health Research Institute

Overview

- Mission & Objectives of the Clinical Core
- Who We Are / What We Do
- The ACT Cohort
- Data We Collect
- Future Efforts
- Digital Data Pilot – Aaron Seitz

The Adult Changes in Thought Study

- ACT is a landmark prospective investigation of older adults recruited from a healthcare delivery system, established in 1994.
- ACT focuses on determining risk factors across the life course to better understand risk and etiology of Alzheimer's disease and related dementias (ADRD), with the long-term goal of promoting cognitive health in aging.

Mission of the Clinical Core

- To collect data and samples in support of ACT's research objectives, Program Projects, Cores, Ancillary Studies, and the broader aging and ADRD research community.

U19 Clinical Core objectives are to:

- Grow and maintain a cohort of diverse older adult participants who complete a core battery of tasks & surveys every 2 years (*biennial cohort*). (target n=3000)
- Obtain a consistent set of rigorously collected cognitive, functional, behavioral, psychosocial and clinical measures over time.
- Evaluate for dementia: consensus clinical diagnoses based on DSM IV criteria, then follow these participants annually → (*annual cohort*).
- Obtain new measures / biospecimens as dictated by new scientific interests.
- Facilitate participation in Project and Core activities and Ancillary studies, paying close attention to participant burden.
- Consent participants into the autopsy cohort.

Data Collection: Clinic & Home Visits

Project Manager (& Problem Solver Extraordinaire): Roxanne Muiruri

Clinic Visit Team KPWHRI

Research Specialists: Holly Roberts, Nora van Doren, Tiffany Gaines, Luke Burke, Marilyn Nguyen, Kelsey Aaronson, Maiya Love, Margie Wilcox, Ann Kelley, David Hsu (RSS)

UW Home Team

Coordinator: Cathy Hutchinson

Psychometrist supervisor -Patti Boorkman*

Psychometrists- Jared Lopes, Isabel Cheeks

Data management -Duryah Mohamath, Virginia Fulcher (Jenny)

** training and certification of new staff, ongoing monitoring & refresher training to ensure fidelity to protocol and consistency between clinic & home visits, and consistency over time*

Clinical Consensus Team

- Project Coordinator: Cathy Hutchinson
- Physicians: Wayne McCormick & James Bowen conduct exams at the participant's home on those with a CASI score <86.
- Neuropsychologist: Sue McCurry interprets neuropsychological tests (detailed testing conducted at home by Jared Lopes and Isabel Cheeks).
- Chart Abstractors: Margie Wilcox, Nora van Doren, Leslie Nemerever, Ann Kelley abstract relevant information from medical records.
- Monthly Meeting: to review findings and determine diagnosis according to DSM IV criteria (DSM-V criteria also noted):
  - Meets criteria for dementia → annual cohort or ineligible.
  - No or mild cognitive impairment → biennial cohort.

ACT Enrollment

We randomly invite Kaiser Permanente Washington Health members who are:

- At least 65 years of age
- Free from dementia at time of enrollment
- Able to speak and read English and sufficient visual and hearing abilities to complete tasks.
- Enrolled in the health plan for at least 2 years
- Primary health care clinic is in the greater Seattle area of King County

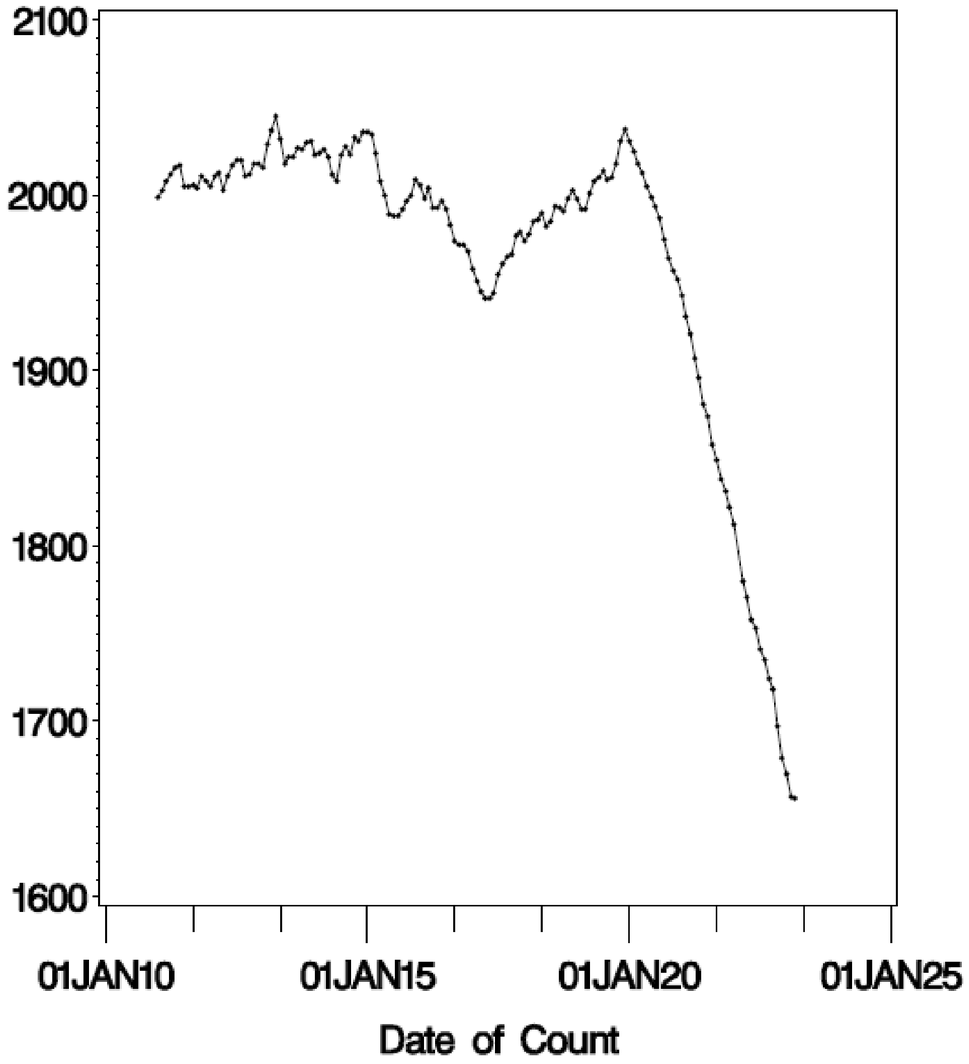
Participants receive an invitation letter with a flyer describing the study and are called (by the KPWHRI Survey Research Group) to determine interest and eligibility, and to schedule their baseline assessment.

History of Participant Enrollment

- **> 6200** participants since cohort inception
- Original Cohort: 1994-96 (n=2581; 58 active – 36 in biennial cohort, 22 in annual)
- Expansion Cohort: 2000-02 (n=811; 80 active: 62 biennial cohort, 18 in annual)
- Continuous Enrollment Cohort: 2005 – present (>2800).
- Total biennial cohort: **1918***; annual cohort 160

* As of May 1, 2024

Biennial Cohort Size 2010- 2023



Sample Diversification Workgroup

- Team: Nicole Gatto, Pamela Shaw, Sundary Sankaran, Sarah Tom, James Ralston, Roxanne Muiruri, Andrea LaCroix, Paul Crane, Linda McEvoy
- Goal: Expand the biennial cohort to 3000 participants, with >20% from groups under-represented in research
- Strategies: Oversampling, updated recruitment materials & consent form, new clinic in Renton, updated catchment primary care clinics.

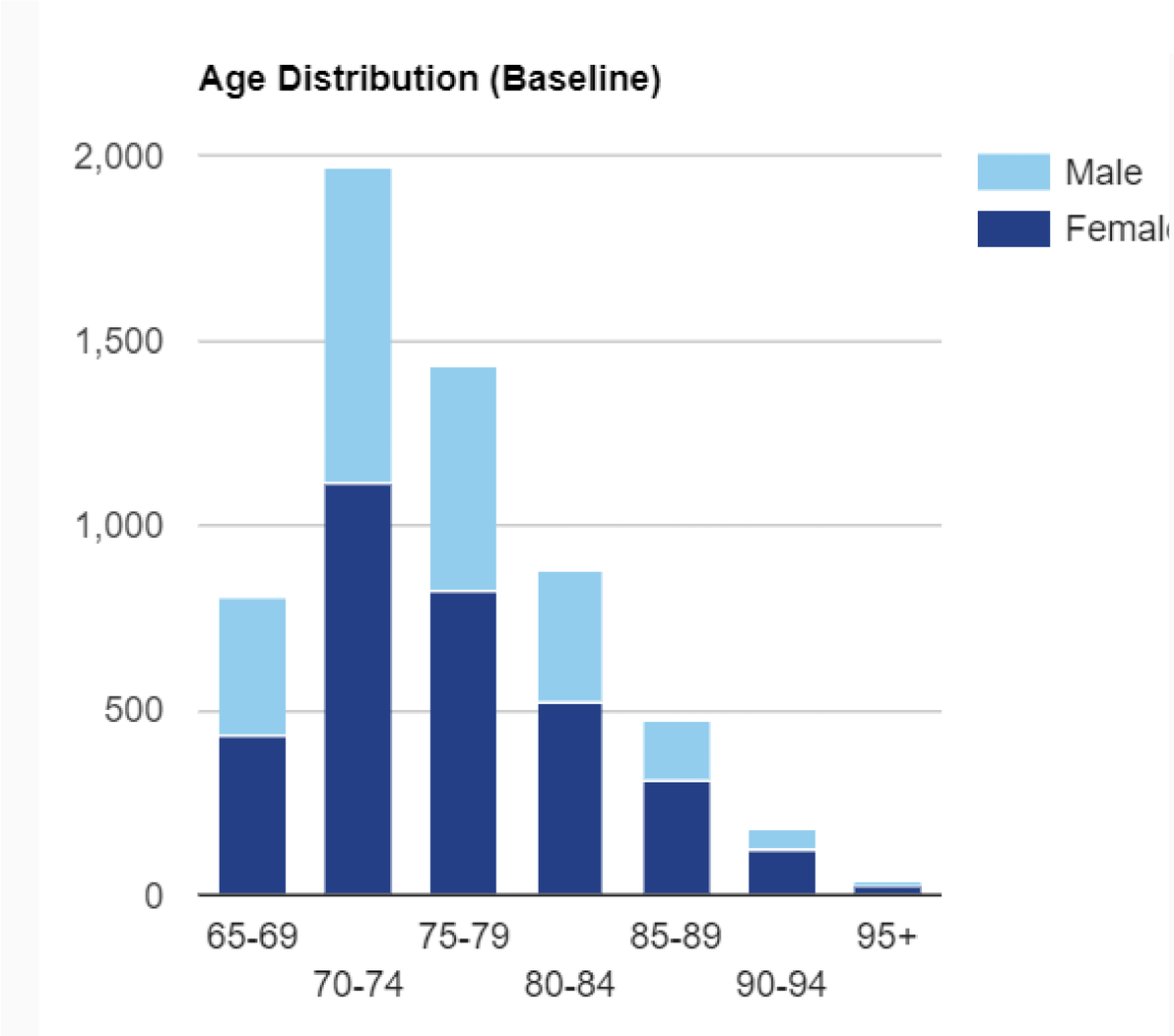
Cohort Diversity: Race

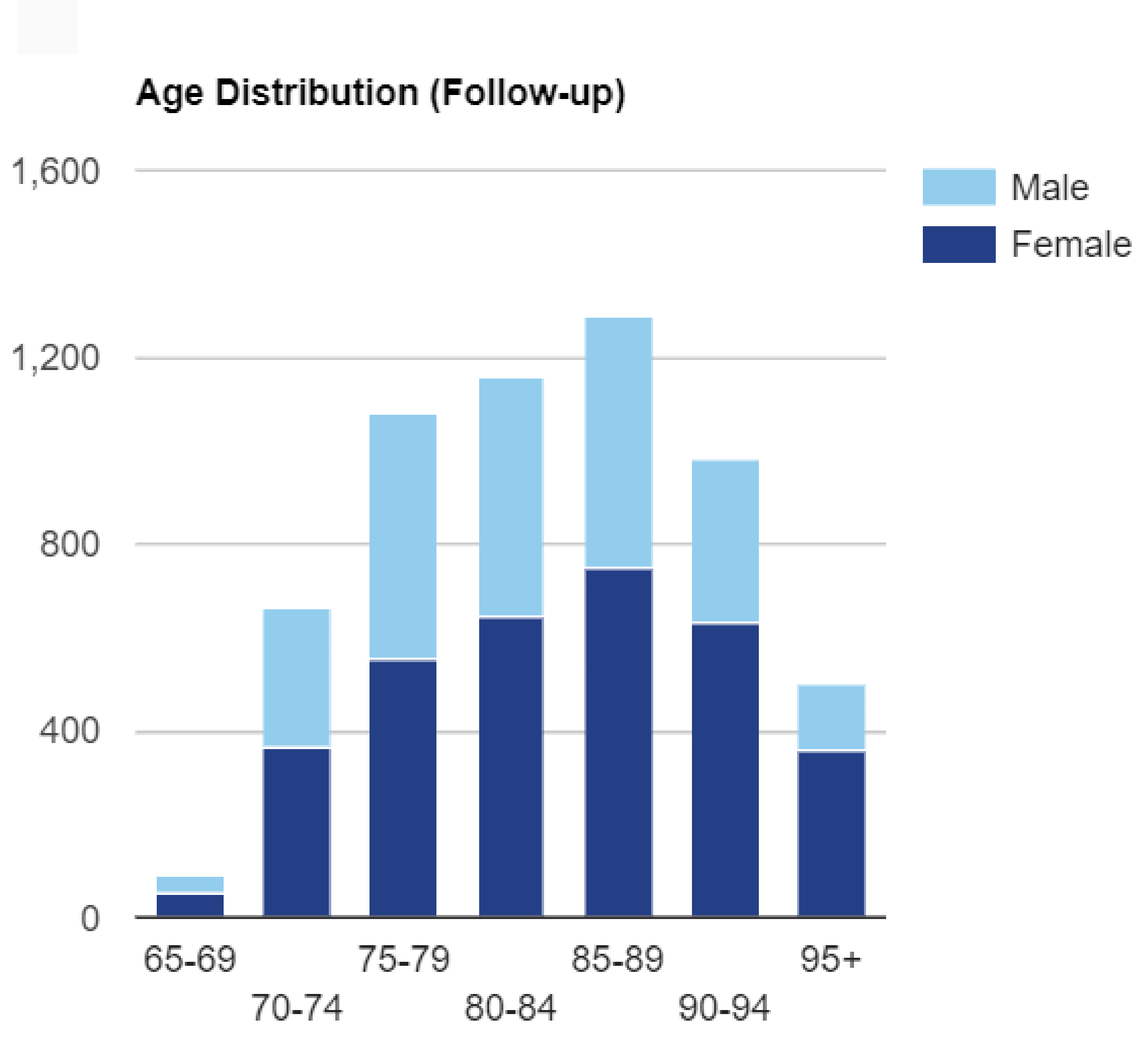
	New Enrollees		Biennial Cohort		Ever Enrolled	
	N	%	N	%	N	%
Asian	113	**23**	158	8	307	5
Black/ African American	60	**12**	101	5	275	4
Native American	7	1	10	1	23	1
Pacific Islander	3	< 1	4	< 1	15	1
White	236	**49**	1548	80	5329	85
Multiple	30	6	41	2	84	1
Other/Unknown	32	7	63	3	212	3
Total	**481**	100	**1925**	100	**6245**	100

Cohort Diversity: Hispanic Ethnicity

	New Enrollees		Biennial Cohort		Ever Enrolled	
	N	%	N	%	N	%
Hispanic	71	**15**	112	6	217	3
Non-Hispanic	390	81	1773	92	5901	95
Unknown	20	4	40	2	127	2
Total	481	100	1925	100	6245	100

Cohort Characteristics





Types of Data we Collect (not inclusive!)

Demographics: sex/gender, race/ethnicity, education, marital status, occupation, income

Cognitive Function: Cognitive Abilities Screening Instrument (CASI); Trails A & B, Fluency, Clock Drawing, Constructional Praxis, Activities of Daily Living, Logical Memory I & II (baseline only)

Health Behaviors: smoking, alcohol use, vitamins, diet questions, sedentary behavior, physical activity, sleep

Medical History: perceived health, hospitalizations, cardiovascular and diabetes history, medications, fractures, brain injury, etc.)

Physical Function: gait speed, hand grip strength, balance test and chair stands

Sensory Function: vision and hearing history.

Psychosocial Measures: Center of Epidemiologic Studies Depression Scale CES-D, social support, life quality and satisfaction, energy, and fatigue.

Anthropomorphic measures & blood pressure: weight; height; waist, hip, neck circumference.

Family History: age of parents at birth, medical history, history of memory problems.

Environment: neighborhood characteristics

Future Efforts

- Evaluate and augment retention strategies
- Create a workgroup to facilitate enrollment into the autopsy cohort.
- Create a biorepository:

  Project Manager: Chay Davis Phlebotomists: Shaula Levy, Marilyn Nyugen & Xavier Acuna.

  - Collect, process and store samples from all willing participants (at MPE).
  - Partnership with NCRAD to obtain plasma biomarkers of AD pathology & neural injury.
  - Competitive revision proposal to equip the new Renton lab with centrifuge & freezer, and to enable home phlebotomy (to be reviewed in June).
- Digital Data Collection

Digital Data Collection for the ACT Study

Aaron Seitz
Professor, Psychology; Game Design; Rehabilitation Sciences
Director, Brain Game Center for Mental Fitness and Well-being
Northeastern University

So where are we today?

We developed a prototype of digital assessments

Some of the digitized tasks

- Speech Based Tasks
  - Verbal Fluency
  - Logical Memory
  - Word Lists
  - Verbal Paired Associates
  - Boston Naming

Speech Based Tasks

Boston Naming

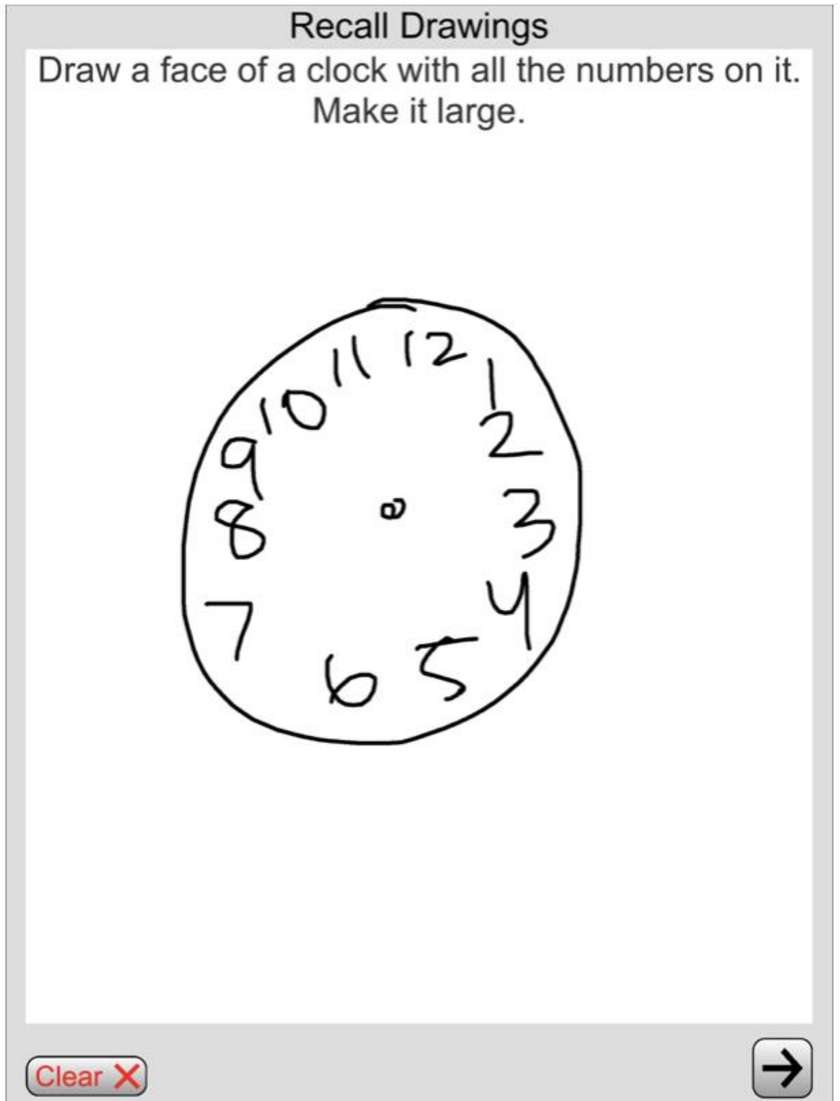
Verbal Fluency

What do we have digitized?

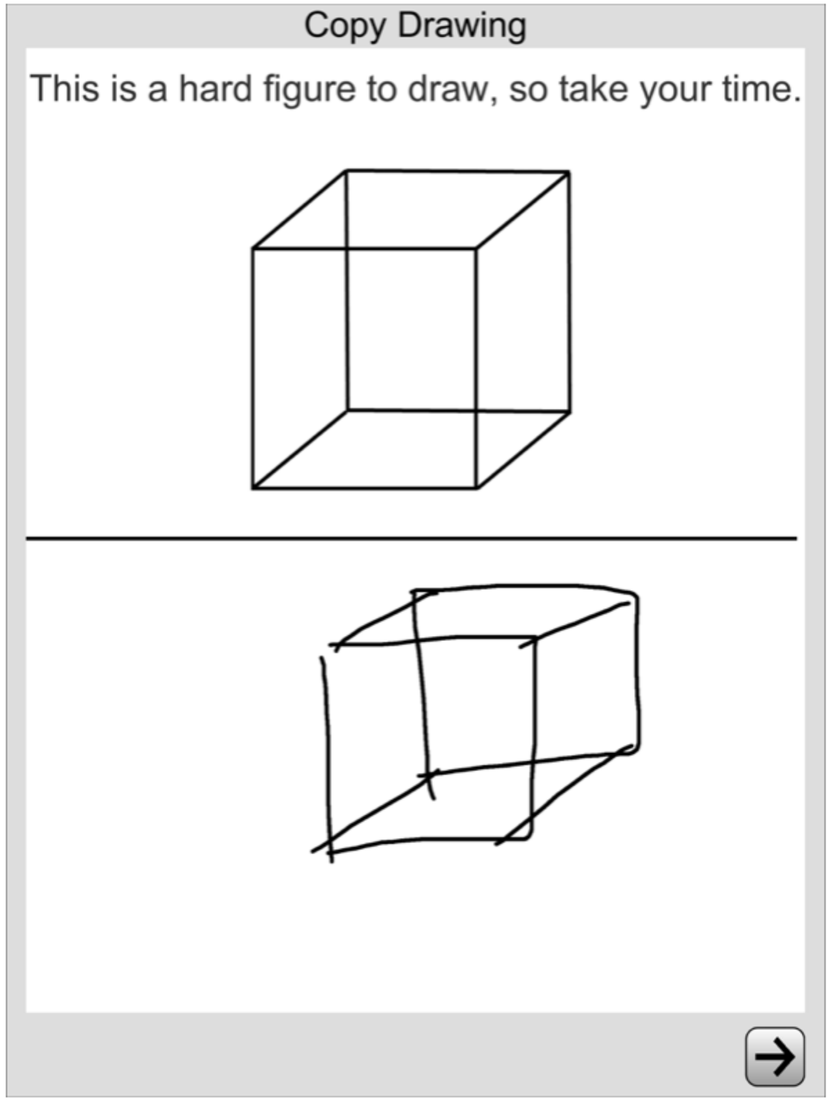
- Speech Based Tasks
  - Verbal Fluency
  - Logical Memory
  - Word Lists
  - Verbal Paired Associates
  - Boston Naming
- Drawing Tasks

Drawing Tasks

Clock Drawing



Constructional Praxis



What do we have digitized?

- Speech Based Tasks
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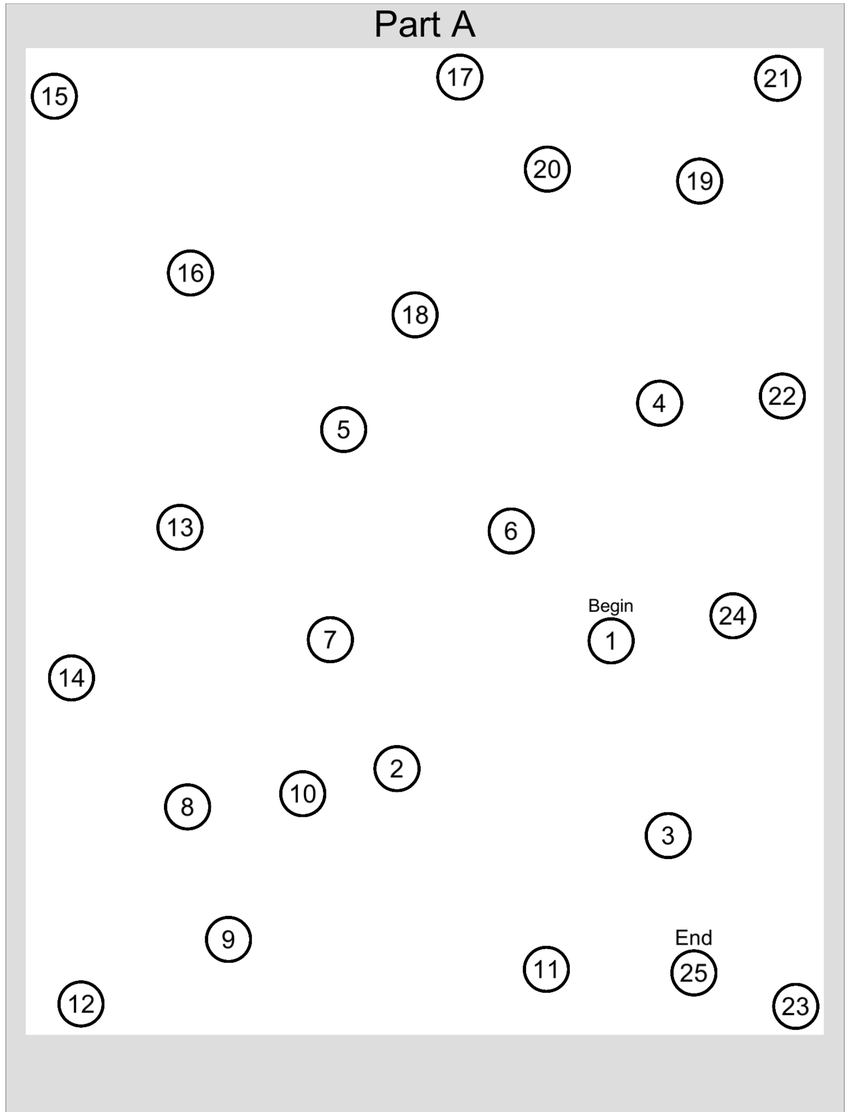
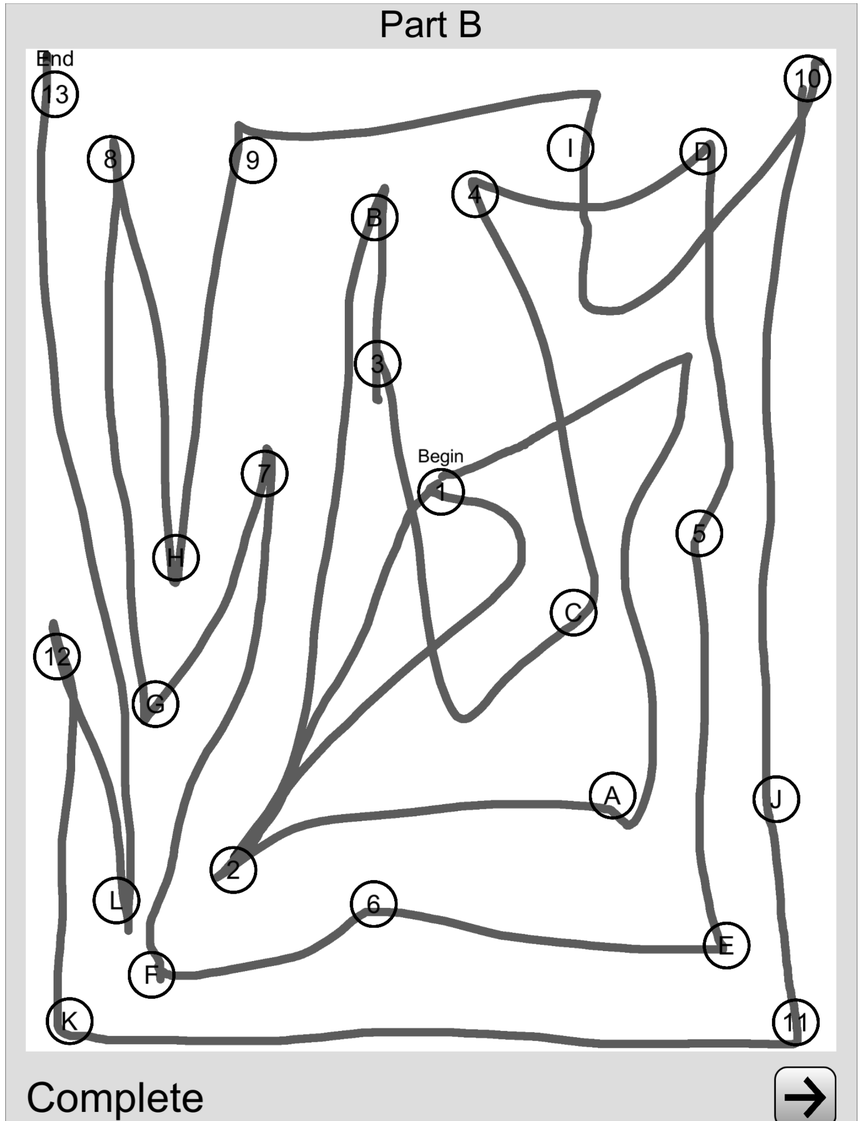
  - Boston Naming
- Drawing Tasks
- Trail Making

Trail Making Task

Trails A



Trails B



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We conducted feasibility studies in older adults in California and an acceptability pilot in ACT cohort

We are developing a new “Interviewer Application”

Instructions

LM-AT

Please listen to instructions.

Digital Data Entry

I am going to read you a little story of just a few lines. Listen carefully and try to remember just the way I say it, as close to the same words you can remember. When I am through, I want you to tell me everything I read to you. You should tell me all you can remember, even if you are not sure. Are you ready?

- **Stories should be read slowly, but with a natural pace and tone.**
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Anna ?	Thompson ?	of South ?	Boston ?	employed ?	as a cook ?
in a school ?	cafeteria ?	reported ?	at the City Hall ?	Station ?	
that she had been held up ?	on State Street ?	the night before ?			
and robbed ?	of fifty-six dollars. ?	she had four ?			
small children, ?	the rent was due ?	and they had not eaten ?			
for two days. ?	The police, ?	touched by the woman's story ?			
took up a collection for her ?	for her ?				

Check All Correct

Record Audio/Stop Recording Audio

00:00

00:00

Auto-scoring

CASI

Total Score: 51

24. What is this?
(show one at a time, any order OK. Show item: 2 sec.; if unable, place in hand: 4 sec. Objects either named or spontaneously or repeated correctly after coaching.)

Spoon

OBJA
- (•) 1
- ( ) 0

Coin

- (•) 1
- ( ) 0

Toothbursh

OBJB
- ( ) 1
- (•) 0

Key

- (•) 1
- ( ) 0

Comb

- ( ) 1
- (•) 0

So where are we today?

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We are developing a new “Interviewer Application”

Second stage pilots, including interviewer app, are planned for Summer 2024

Thank you for your attention!
Questions and Comments Welcome.

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