



# Wisconsin Alzheimer's Disease Research Center

UNIVERSITY OF WISCONSIN  
SCHOOL OF MEDICINE AND PUBLIC HEALTH

## Providing Feedback to Research Participants: Cognitive Data

Fall ADC meeting  
San Diego  
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# Outline

- Brief Background
- Advantages
- Downside
- Process

# Background

- Literature discussing participation in research
  - Alzheimer's disease research, aspects of AD research (Jefferson et al. JAD 2011; Boise et al. Alz Dis. Assoc. Disord. 2017; Williams et al Alz Dis Assoc Disord 2010)
  - Specific to Under-represented groups (George et al AJP 2013; Chao et al Gerontol. 2011; Williams et al Gerontol. 2011; Gelman J Gerontol SW 2010)
  - Treatment trial (Calamia et al PLoS One 2016; Carr et al. Alz Dis Assoc Disord 2010) v. observational studies (Jefferson et al JAD 2011)
  - Specific to preclinical studies (Grill et al. Alz Dem. 2013; Grill et al Neurobiol Aging 2016)

# Background

- Feedback about results makes the list; both as a encouragement and as a deterrent
  - When given - As a reason why people participate
  - When not provided – seen as lacking transparency

**Table 1. Research Designs and Interest in Study Participation.**

	Significant increase likelihood of participation N(%)	Not a major factor in decision to participate N (%)	Significantly decrease likelihood of participation N(%)
<b>Benefits for participant</b>			
Study topic interests me	61(92.4)	5(7.6)	0 (0%)
Researcher contacts me	41(62.1)	25(37.9)	0 (0%)
Help my health	65(98.5)	1(1.5)	0 (0%)
Get feedback on my health	62(93.9)	4(6.1)	0 (0%)
Receive payment	11(16.4)	54(83.1)	0 (0%)
<b>Benefits for others</b>			
Leads to treatment for disease	63(95.5)	3(4.5)	0 (0%)
Advances science	59(89.4)	7(10.6)	0 (0%)
Help others	62(93.9)	4(6.1)	0 (0%)
<b>Medical procedure</b>			
Have MRI	10(15.6)	47(73.4)	7(10.9)
Have lumbar puncture (spinal tap)	2(3.1)	19(29.2)	44(67.7)
Provide blood sample	10(15.4)	54(83.1)	1(1.5)
<b>Types of interventions</b>			
Diet	6(9.8)	40(65.6)	15(24.6)
Medication	4(6.2)	27(41.5)	34(52.3)
Exercise	30(45.5)	36(54.5)	0 (0%)
Meditation	13(19.7)	40(60.6)	13(19.7)
Acupuncture	13(19.7)	33(50)	20(30.3)
Yoga	14(21.5)	30(46.2)	21(32.3)
Computer-based	24(36.9)	37(56.9)	4(6.2)
<b>Intervention Characteristics</b>			
1 month long	24(36.9)	41(63.1)	0 (0%)

Calamia M, Bernstein JPK, Keller JN (2016) I'd Do Anything for Research, But I Won't Do That: Interest in Pharmacological Interventions in Older Adults Enrolled in a Longitudinal Aging Study. PLOS ONE 11(7): e0159664.  
<https://doi.org/10.1371/journal.pone.0159664>

<http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0159664>

# Background

- Feedback about results makes the list; both as a encouragement and as a deterrent
  - When given - As a reason why people participate
  - When not provided – seen as lacking transparency
- Others have shown that disclosure of diagnosis can be reassuring (clinical not pre-clinical diagnosis) (Carpenter et al. JAGS 2008)

# Advantages

- Build trust and confidence in your program
  - Greater transparency
  - Concierge service
- Pay it back
  - Providing personal and directly relevant information – direct benefit
- Recruitment and Retention
  - Monitoring for change over time

# Downside

- Requires an investment
  - Personnel
- Boundaries between research and health care
- Changing outcomes
  - Are we changing the participant trajectories

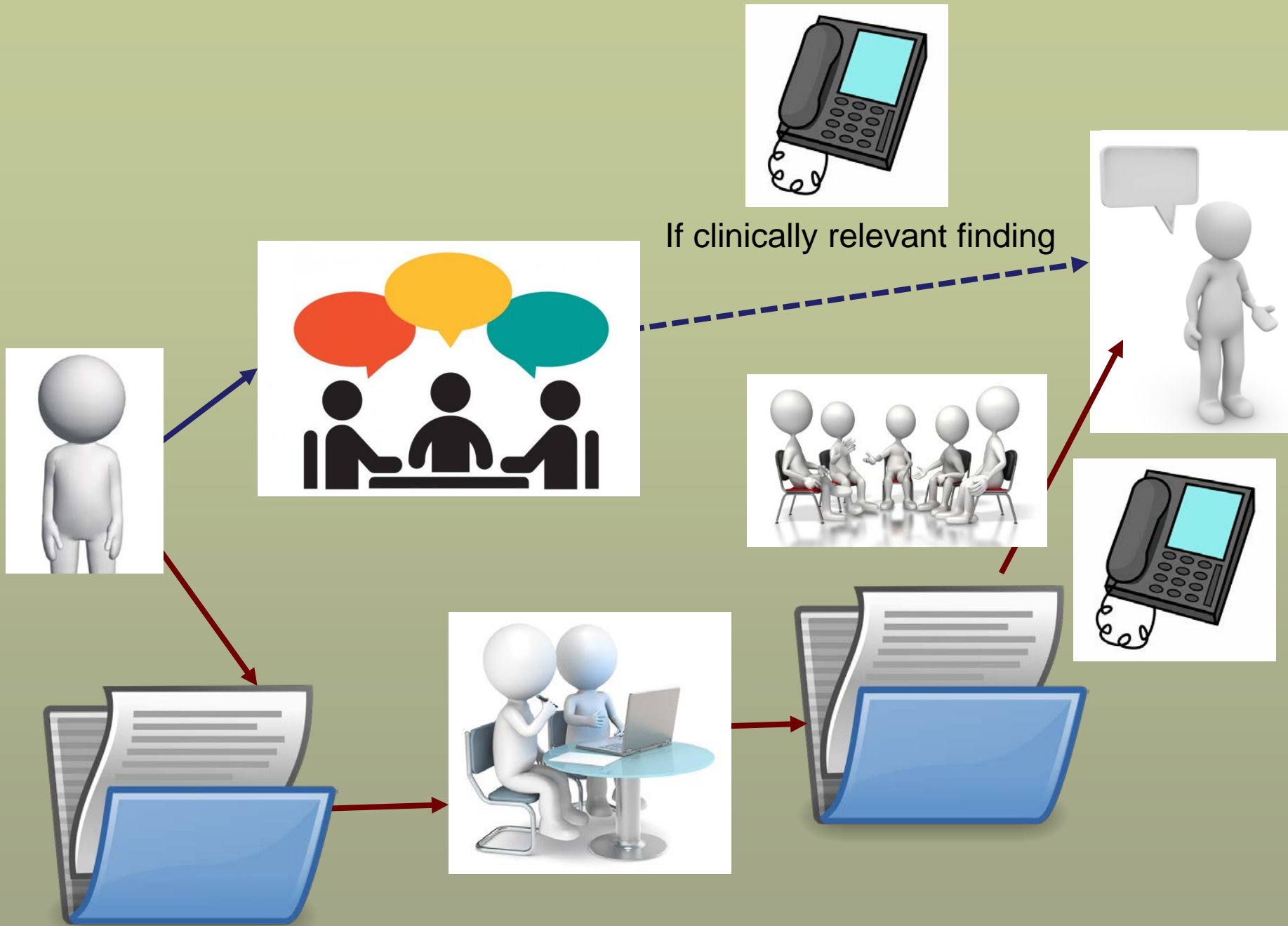


# Process

- Obtain consent for optional meeting
- Team reviews cognitive and other clinical data at diagnostic consensus conference
- Possible outcomes:
  - No change in diagnosis
  - Change in diagnosis
    - New diagnosis of dementia, MCI or impaired not MCI
    - Revert to normal
  - Latter would trigger a clinician phone call

# Process

- For AA-FAiM participant who opts into “wrap around” staff call to schedule visit (phone or in person)
- If participant has impairment, include study partner
- Staff starts compiling Summary Document
- Clinician edits and finishes first draft
- Feedback provided, typically 15-30 minutes
- Document in participant contact record and indicate follow-up instructions



### **Memory and Thinking tests:**

At your visit, you completed several memory and thinking tests. Depending on the test, your scores were compared to others your age, your race, and/or with your education. These comparisons tell us whether you are like the “normative sample”, in other words average, or if you are below or above average. We will watch for changes in scores over time.

	Baseline 6/2/16	Annual Year 1	Annual Year 2
Memory and Thinking tests	Scores ranged from Borderline to Superior. Some trouble with auditory recall (list of words).	A couple scores lower than last year. Still struggling with auditory recall and weakness with drawing. All other scores in average to very superior range.	

Most recent findings:

**Strengths:** Many! Fluency; speeded divided attention, naming, auditory attention

**Summary:** Isolated weakness in memory. Shows up on auditory verbal memory and on recall of a design. We think this is consistent with a diagnosis of mild cognitive impairment.

### **Medical Exam findings:**

	Baseline 2/8/12	Annual Year 1
Blood Pressure	166/75	152/76

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	Baseline 2/8/12	Annual Year 1	Annual Year 2	Annual Year 3**	Annual Year 4	Annual Year 5
Memory and Thinking tests	Scores ranged from average to superior	Stable	High average to superior	Flagged. Low average Attention and Global Cognition	Scores improved	

Most recent findings:

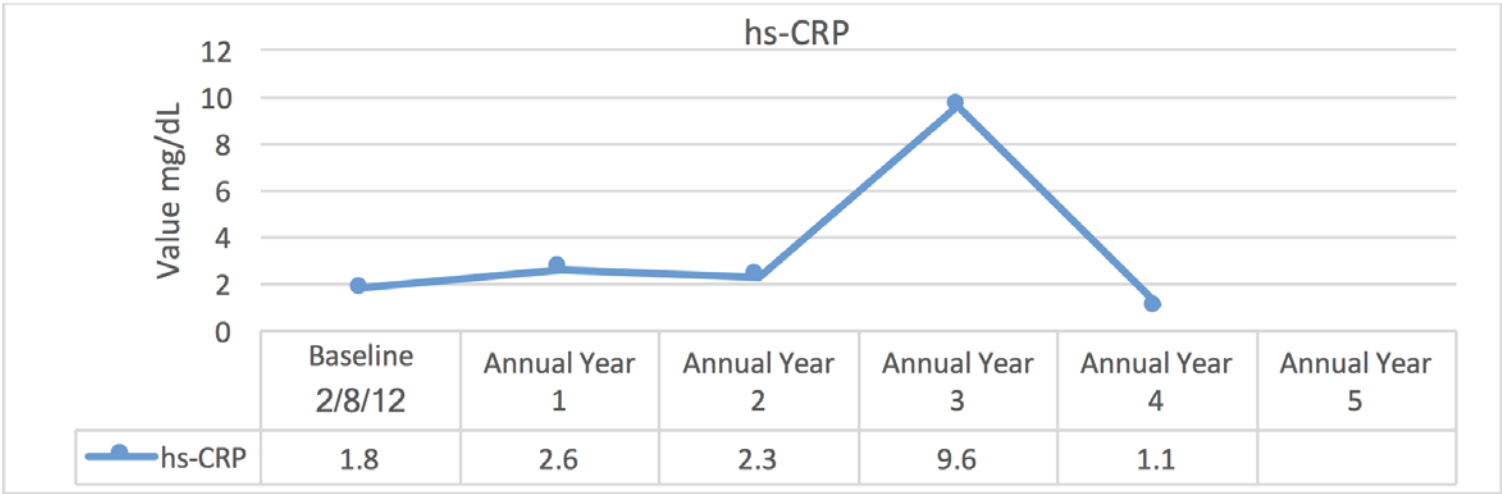
**Strengths:** Fluency, speeded tasks.

**Summary:** In year 3, your scores on a few tests were lower than expected. For example, the one where you connect the circles in order, going back and forth between numbers and letters. This year, your scores were better. You are cognitively healthy.

**Medical Exam findings:**

	Baseline 2/8/12	Annual Year 1	Annual Year 2	Annual Year 3	Annual Year 4	Annual Year 5
Blood Pressure	139/67	159/71	98/65	168/75	173/82	

Hs-CRP: A high-sensitivity C-Reactive Protein (hs-CRP) test is a measuring a protein that increases in the blood when there is inflammation. If it is high once, it is a sign of infection. If it is high chronically, it may be there is underlying heart disease. It's important to pay attention to the pattern of changes in levels over time.



**Summary:** Great reading this year.

# Typical follow-up

- With summary form, mail out:
  - NIH-NIA ADEAR pamphlets
  - Handouts on MIND and Mediterranean diets
  - Information about our exercise classes
  - Recommendation to review laboratory findings with PCP



Thank you for your attention  
Questions and Comments?



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