

Retention Practices in the ADC System

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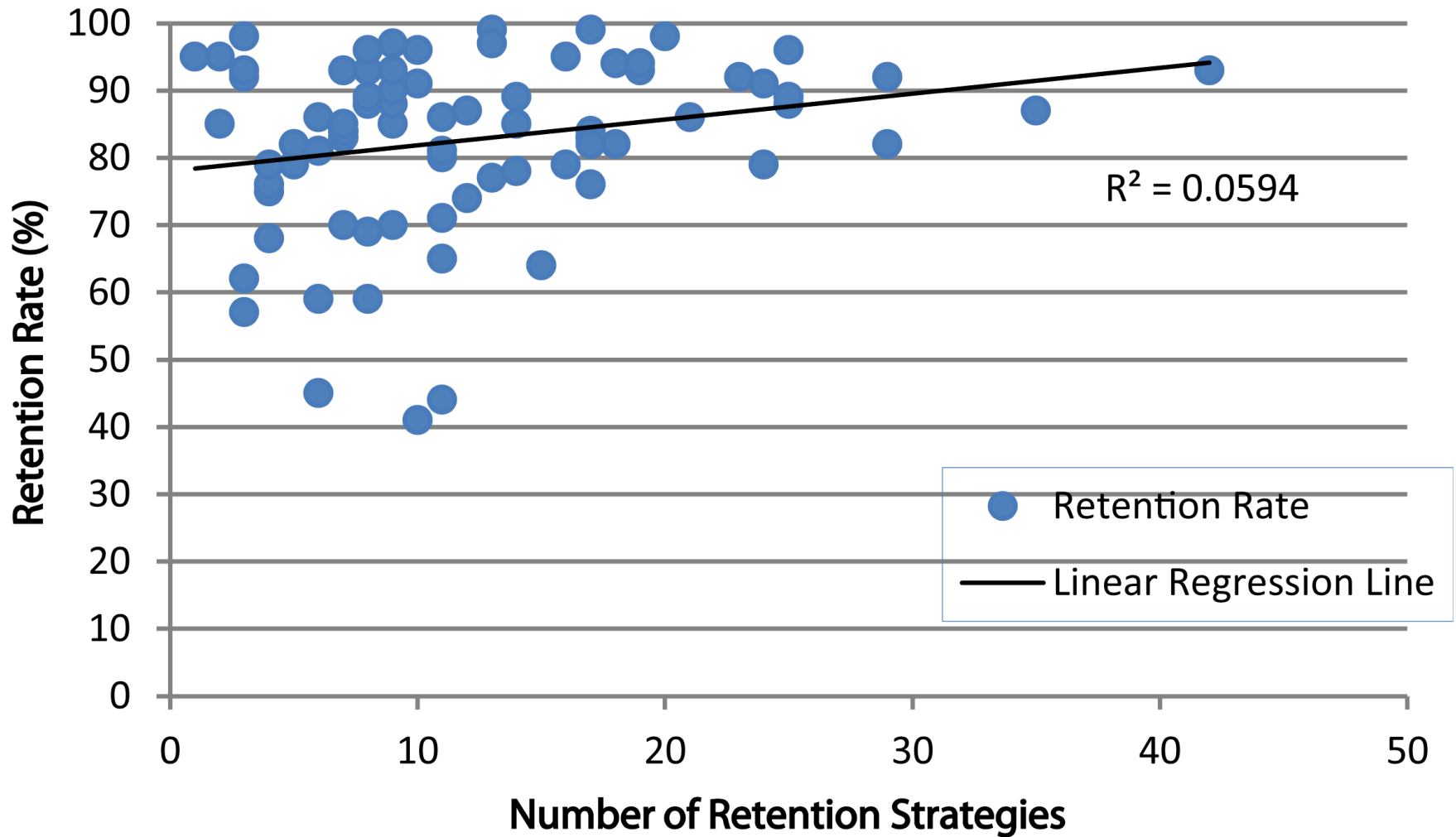
AD Trial Retention Rates

Trial	N	Active Completers	Placebo Completers	Overall Retention
Gamma secretase inhibitor	51	32/36 = 0.89	12/15 = 0.80	0.86
Dimebon	183	78/89 = 0.88	77/94 = 0.82	0.85
Rosiglitazone	518	106/122 = 0.87	336/389 = 0.86	0.85
High dose B vitamin	409	204/240 = 0.85	140/169 = 0.83	0.84
Rivastigmine patch	1195	704/893 = 0.79	266/302 = 0.88	0.82
Estrogen replacement	120	65/81 = 0.80	32/39 = 0.82	0.81
Galantamine	978	539/692 = 0.78	240/286 = 0.84	0.80
Rofecoxib	351	179/240 = 0.74	88/111 = 0.79	0.76
DHA	402	178/241 = 0.74	129/161 = 0.80	0.76
Bapineuzumab	234	92/122 = 0.75	87/107 = 0.81	0.76
AN1792	372	223/299 = 0.74	53/73 = 0.73	0.74
Idebenone	536	281/407 = 0.69	96/129 = 0.74	0.72
Atorvastatin	640	207/314 = 0.66	245/326 = 0.75	0.71
Galantamine	636	266/423 = 0.63	172/213 = 0.81	0.69
Tarenflurbil	1684	506/862 = 0.59	540/822 = 0.66	0.62

Themes of Retention Strategies

- Community involvement
- Study identity
- Study personnel
- Study description
- Contact and scheduling methods
- Reminders
- Visit characteristics
- Benefits of study
- Financial incentives
- Reimbursement
- Nonfinancial incentives
- Special tracking methods

Retention Tactics

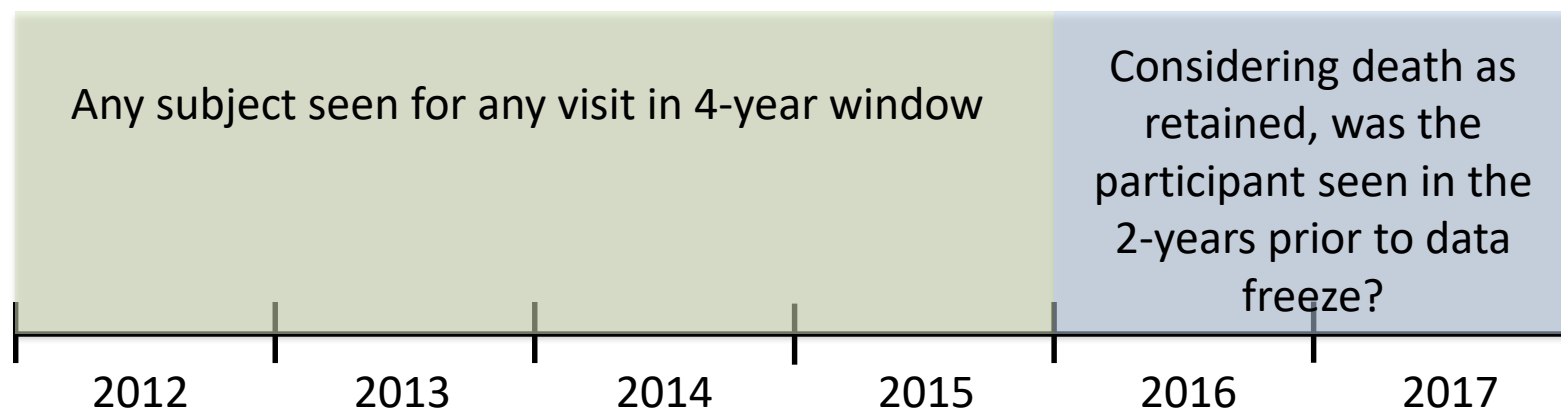


Methods

- Survey of ADC ORE Core Leaders
 - Requesting collaboration with Clinical Cores
- Based on strategies identified by Robinson and colleagues
- Survey developed at UCI, vetted by two geographically dispersed ADCs (KU, OHSU)
- Distributed via REDCap
- Survey results compared against NACC retention data

NACC Retention Rates

- NACC data request from all centers completing the survey
 - Response rate: 25/31 (81%)
- 21 of 25 center's data used (3 recently funded with inadequate retention data; one recently stopped contributing NACC data)
 - N=14,029
 - N=5,891 newly enrolled participants in the 4-year window



Analyses

- Frequencies of survey responses
- Fit a model using center retention survey scores and center retention performance
- Multivariable model, stepwise variable selection based on AIC
- Pairwise correlations between survey strategy scores and retention rates

Model Covariates

- Overall retention strategy score
- Time since baseline visit
- Diagnostic status (normal[R], MCI, dementia)
- Race (Caucasian[R], African American, Asian, Other)
- Ethnicity (Non-Hispanic[R], Hispanic)
- Gender (male[R], female)
- Age
- Education
- Study partner type (spouse[R], adult child, other)
- Total ADRC visit length
- ADRC Neuropsychological Test Battery length

[R]: Reference group

Visit Length and Neuropsychological Test Battery Length

- For multivariable models, collapsed categories*

- Visit length

- 0-3 hours
- >3 hours

Total visit length	0-2 h	2-3 h	3-4 h	4-5 h	5-6 h	>6 h
Centers (n)	1	4	7	5	3	1

- Battery length

- 0-2 hours
- >2 hours (range 2-4)

Battery length	0-2 h	2-3 h	3-4 h	>4 h
Centers (n)	15	5	1	0

*based on scarcity of data in some categories and statistical decision based on regression coefficients

	N=25	N=21
Strategy/tactic	ADCs, n (%)	ADCs, n (%)
<i>Study personnel</i>	24 (96)	20 (95)
• Diverse staff	23 (92)	19 (90)
• Identify specific staff members who are responsible for retention of particular participants	20 (80)	16 (76)
• Ensure that specific staff (study clinician) see participants consistently over time	18 (72)	14 (67)
• New staff training on retention	14 (56)	11 (52)
• Annual staff training on retention	9 (36)	6 (29)
• Other	1 (4)	1 (5)
○ Twice annual staff retreat with focus on retention		

Strategy/tactic	ADCs, n (%)	ADCs, n (%)
<i>Contact and scheduling</i>	25 (100)	21 (100)
• Use data capture system (e.g., REDCap) to monitor visit windows	23 (92)	20 (95)
• Use alerts to study staff to send visit reminders	17 (68)	14 (68)
• Use automated email systems to remind participants about visits	3 (12)	3 (14)
• Use automated telephone systems to remind participants about visits	4 (16)	2 (10)
• Use automated text messaging systems to remind participants about visits	1 (4)	0 (0)
• Other <ul style="list-style-type: none"> ○ 'personal' touch calls or emails from familiar staff 	1 (4)	0 (0)

Strategy/tactic	ADCs, n (%)	ADCs, n (%)
<i>Special tracking methods</i>	18 (72)	14 (67)
<ul style="list-style-type: none"> • Maintain phone tree of individuals to contact if the participant cannot be reached 	16 (64)	12 (57)
<ul style="list-style-type: none"> • Attend patient clinical visits as a means to contact them and request completion of study visits 	10 (40)	9 (43)
<ul style="list-style-type: none"> • Follow participants on social media and send private messages to remind of appointments or reach out if difficult to reach through traditional modes of communication 	0 (0)	0 (0)
<ul style="list-style-type: none"> • Other <ul style="list-style-type: none"> ○ No shows triaged to more intense follow-up ○ Letters asking for contact if phone number has changed 	2 (8)	2 (10)

Strategy/tactic	ADCs, n (%)	ADCs, n (%)
<i>Visit characteristics</i>	25 (100)	21 (100)
• Offer breaks during visits	25 (100)	21 (100)
• Permit telephone completion of study partner activities	25 (100)	21 (100)
• Follow participants by phone if it becomes impossible for them to attend visits due to disease severity	25 (100)	21 (100)
• Offer water and snacks during visits	23 (92)	19 (90)
• Schedule visits around participants' needs/energy level	22 (88)	22 (88)
• Permit splitting of visits into 2 or more sessions over 2 or more days	21 (84)	18 (86)
• Permit splitting of visits into 2 sessions in a single day	20 (80)	16 (76)
• Hold visits at convenient (off site) locations	10 (40)	8 (38)
• Perform home visits	9 (36)	7 (33)
• Hold visits during non-traditional hours (evenings)	5 (20)	3 (14)
• Hold visits during non-traditional days (weekends)	4 (16)	3 (14)
• Other	1 (4)	1 (5)
○ Nursing home visits		

Strategy/tactic	ADCs, n (%)	ADCs, n (%)
<i>Financial incentives</i>	19 (76)	15 (71)
• Provide annual cash payment for completing optional study procedures (e.g., lumbar puncture)	11 (44)	9 (43)
• Provide annual cash payment for completing study visits	9 (36)	8 (38)
• Provide annual non-cash payment (e.g., gift card) for completing study visits	5 (20)	4 (19)
• Provide annual non-cash payment (e.g., gift card) for completing optional study procedures (e.g., lumbar puncture)	5 (20)	5 (24)
• Other	0 (0)	0 (0)

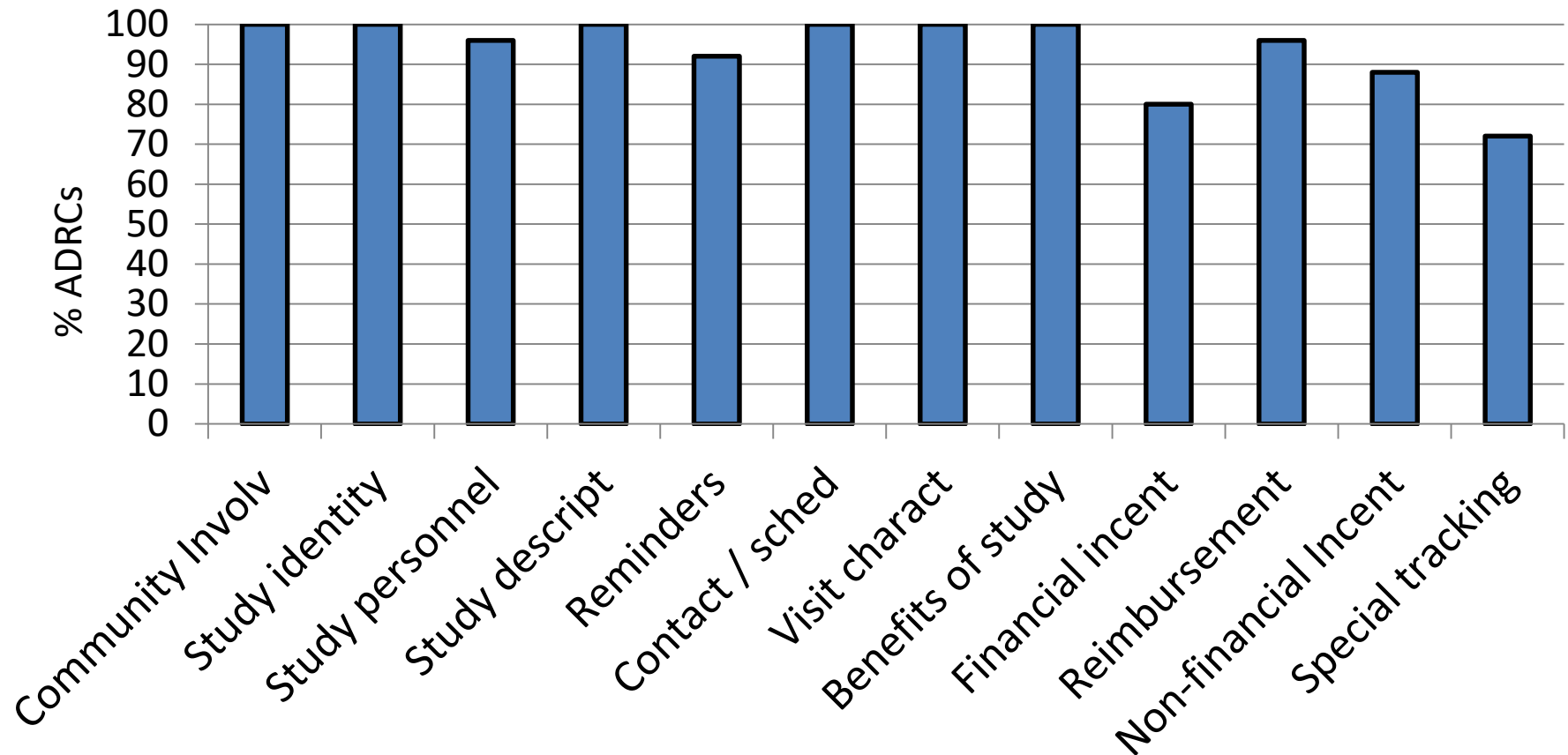
Strategy/tactic	ADCs, n (%)	ADCs, n (%)
<i>Non-financial incentives</i>	22 (88)	19 (90)
• Hold participant gratitude events	21 (84)	18 (86)
• Send seasonal holiday cards	15 (60)	12 (57)
• Offer participants value nominal gifts such as pens, magnets, etc.	13 (52)	10 (48)
• Provide participants awards or certificates of appreciation for milestone visits (e.g., 5- or 10-year interval)	11 (44)	9 (43)
• Send birthday cards	9 (36)	7 (33)
• Hold participant holiday celebrations	5 (20)	4 (19)
• Other	4 (16)	4 (19)
○ ADRC-stamped chocolate bars		
○ Bereavement cards		
○ Birthday telephone calls		



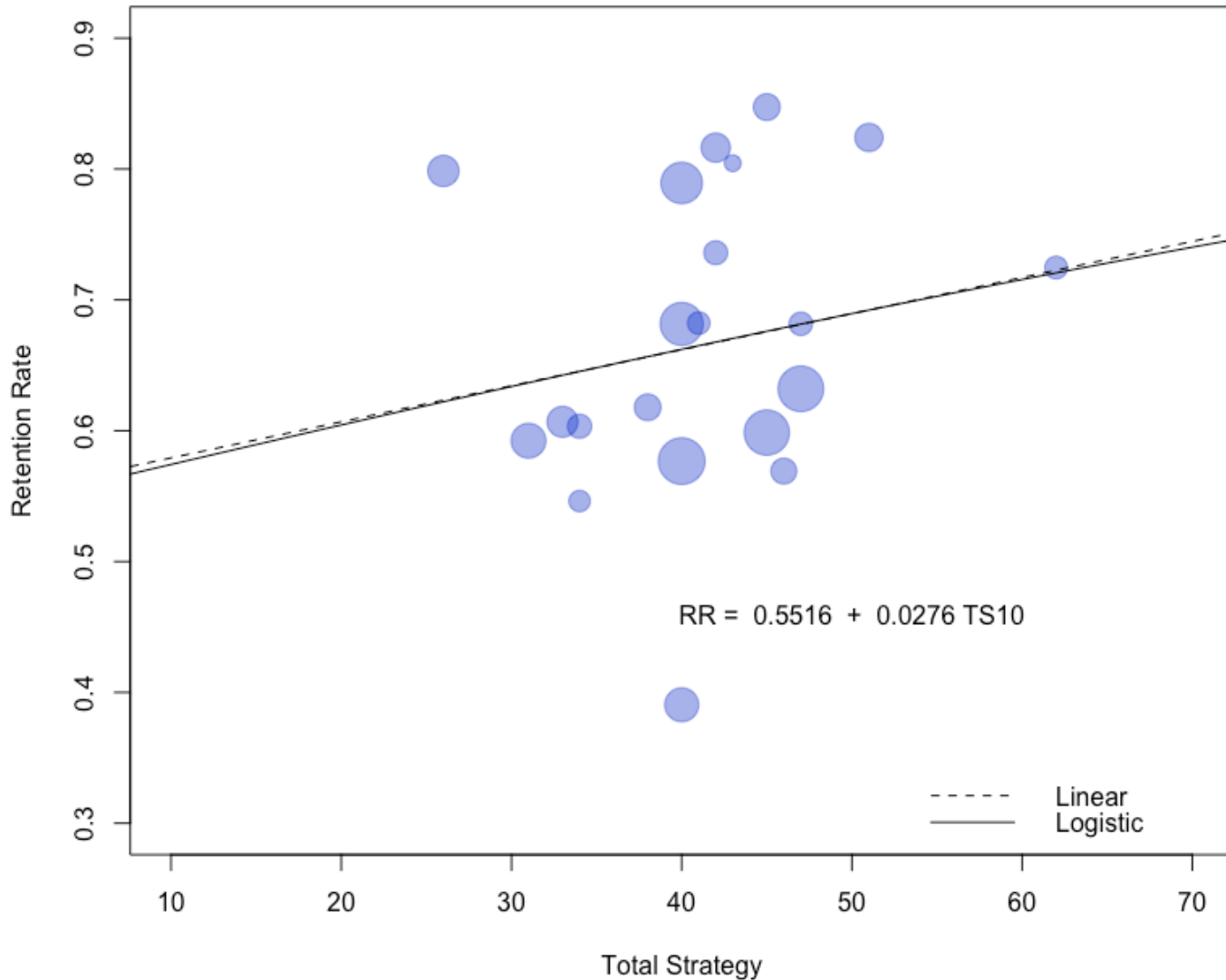
Strategy/tactic	ADCs, n (%)	ADCs, n (%)
<i>Benefits of study</i>	25 (100)	21 (100)
• Provide feedback on annual UDS evaluation to PCP or other provider if requested by participant	22 (88)	19 (90)
• Provide diagnostic results to participants	20 (80)	17 (81)
• Provide feedback on non-UDS evaluations (lab values, evaluations, MMSE, etc) to PCP or other provider if requested by participant	19 (76)	16 (76)
• Provide neuropsychological test results to participants	17 (68)	14 (67)
• Provide laboratory test results to participants	17 (68)	15 (71)
• Offer support groups	17 (68)	14 (67)
• Provide MRI biomarker results to participants	12 (48)	10 (48)
• Provide amyloid PET results to participants	8 (32)	7 (33)
• Provide CSF biomarker results to participants	7 (28)	7 (33)
• Provide FDG PET biomarker results to participants	7 (28)	7 (33)
• Provide genetic test results to participants	3 (12)	3 (14)
• Provide free clinical care (e.g., medication prescriptions) to participants	3 (12)	3 (14)
• Other	1 (4)	1 (5)
• Provide access to a social worker		

Survey Responses

- Mean (SD) = 42 (7) tactics (Range: 26-62)



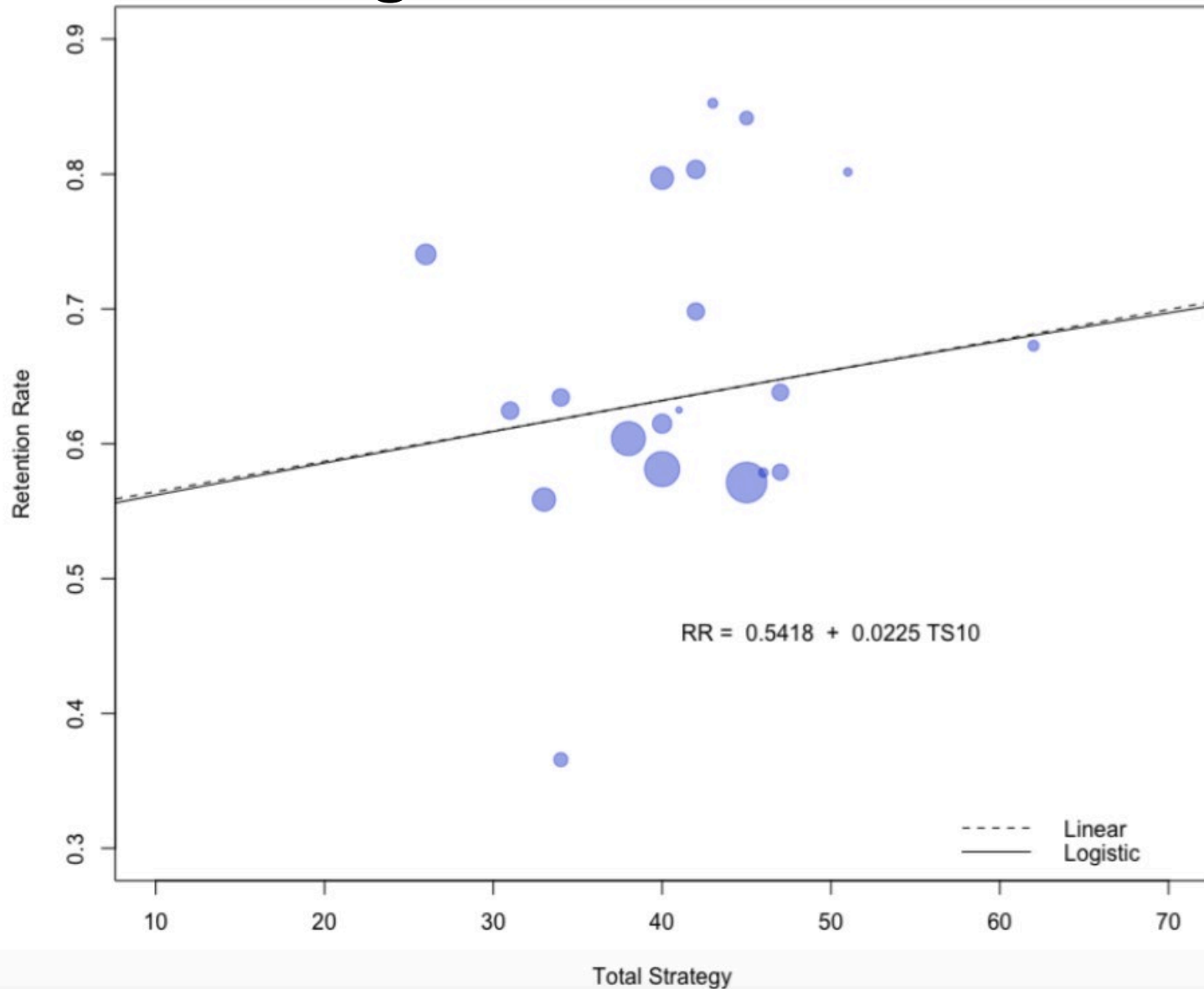
Relationship Between Center Retention Strategies and Retention Rate



Multivariable model results (n=14,029).

Covariate	OR	95% CI	P-value
Total strategy score (x10 units)	1.21	(1.14, 1.30)	<0.0001
• Normal control	-	-	-
• MCI	0.84	(0.77, 0.92)	0.0001
• Dementia	0.59	(0.53, 0.65)	<0.0001
• White race	-	-	-
• Asian race	0.63	(0.51, 0.78)	<0.0001
• African American race	0.77	(0.69, 0.87)	<0.0001
• Other race	0.89	(0.67, 1.16)	0.38
• Non-Hispanic ethnicity	-	-	-
• Hispanic ethnicity	0.69	(0.59, 0.81)	<0.0001
• Spouse/partner partner	-	-	-
• Adult child partner	0.75	(0.68, 0.83)	<0.0001
• Other partner	0.82	(0.74, 0.90)	0.0001
• Male sex	-	-	-
• Female sex	0.81	(0.74, 0.87)	<0.0001
Age (years)	1.04	(1.04, 1.05)	<0.0001
Education (years)	1.05	(1.03, 1.06)	<0.0001
Visit length			
• 0-3 hours	-	-	-
• >3 hours	0.66	(0.59, 0.74)	<0.0001
Battery length			
• 0-2 hours	-	-	-
• >2 hours	1.26	(1.16, 1.38)	<0.0001

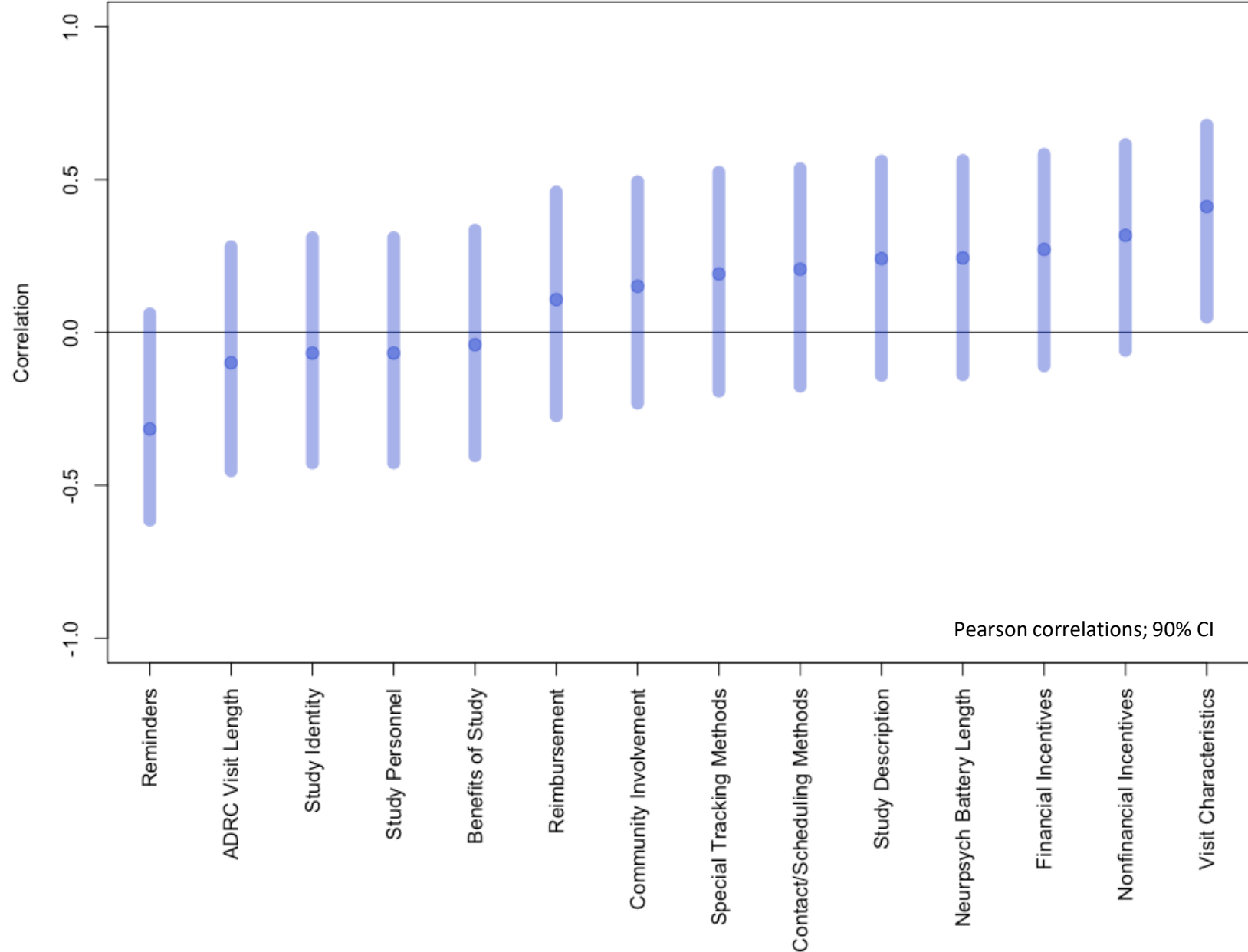
Relationship Between Center Retention Strategies and Retention Rate



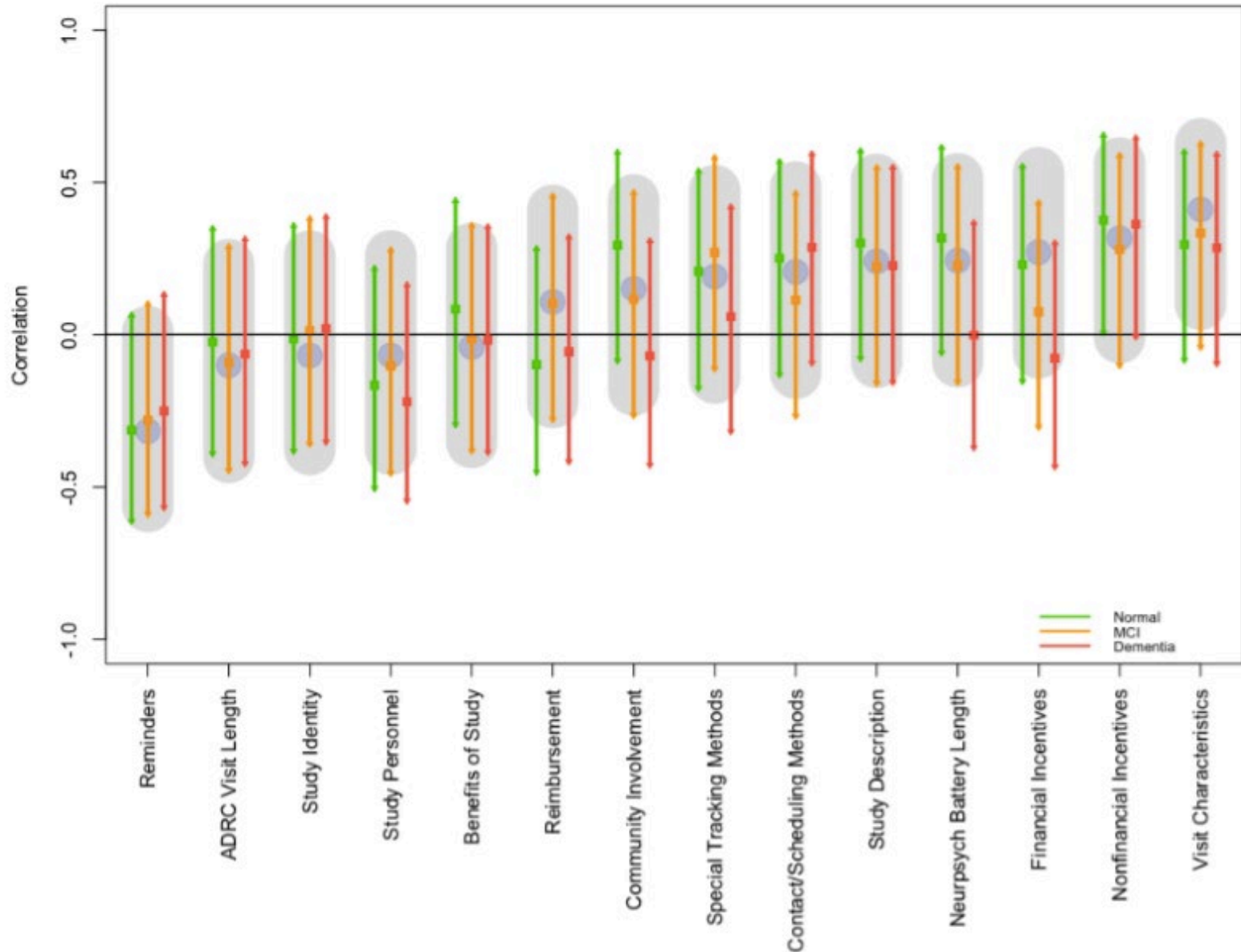
Multivariable model results (n=5,891 new participants).

Covariate	OR	95% CI	P-value
Total strategy score (x10 units)	1.27	(1.14, 1.42)	<0.00001
• Normal	-	-	-
• MCI	0.80	(0.70, 0.91)	0.001
• Dementia	0.57	(0.49, 0.67)	<0.00001
• White race	-	-	-
• Asian race	0.84	(0.63, 1.23)	0.24
• African American race	0.72	(0.61, 0.86)	0.0002
• Other race	0.82	(0.55, 1.23)	0.34
• Non-Hispanic Ethnicity	-	-	-
• Hispanic Ethnicity	0.73	(0.56, 0.95)	0.017
• Spouse/partner	-	-	-
• Adult child	0.74	(0.64, 0.86)	0.0001
• Other	0.82	(0.70, 0.95)	0.01
• Male sex	-	-	-
• Female sex	0.76	(0.68, 0.86)	<0.00001
Age (years)	1.04	(1.03, 1.05)	<0.00001
Education (years)	1.04	(1.02, 1.06)	<0.00001
Time since baseline	0.83	(0.79, 0.88)	<0.00001
Visit length			
• 0-3 hours	-	-	-
• >3 hours	0.70	(0.59, 0.83)	<0.00001
Battery length			
• 0-2 hours	-	-	-
• >2 hours	1.11	(0.97, 1.27)	0.14

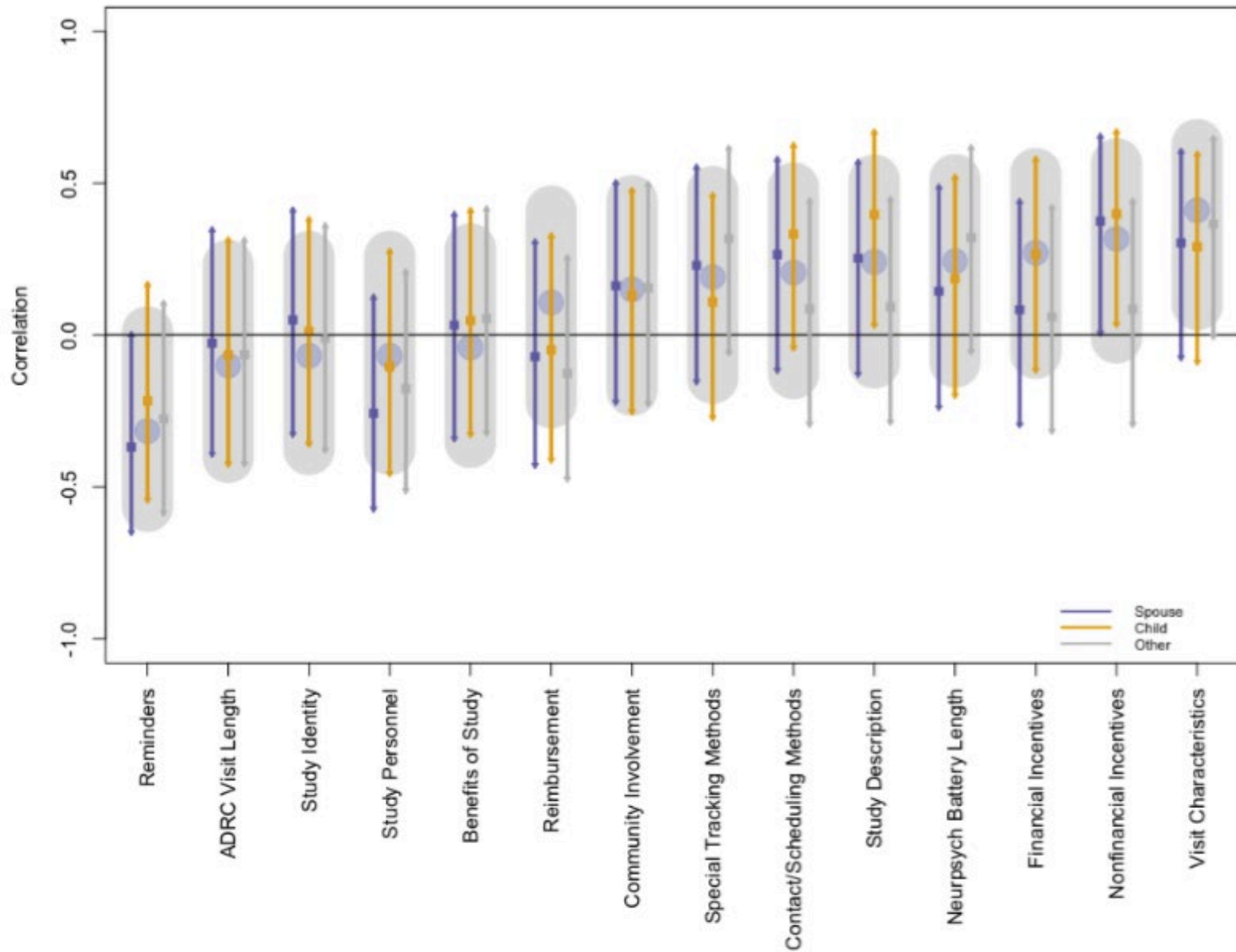
Correlations Between Strategies and Retention



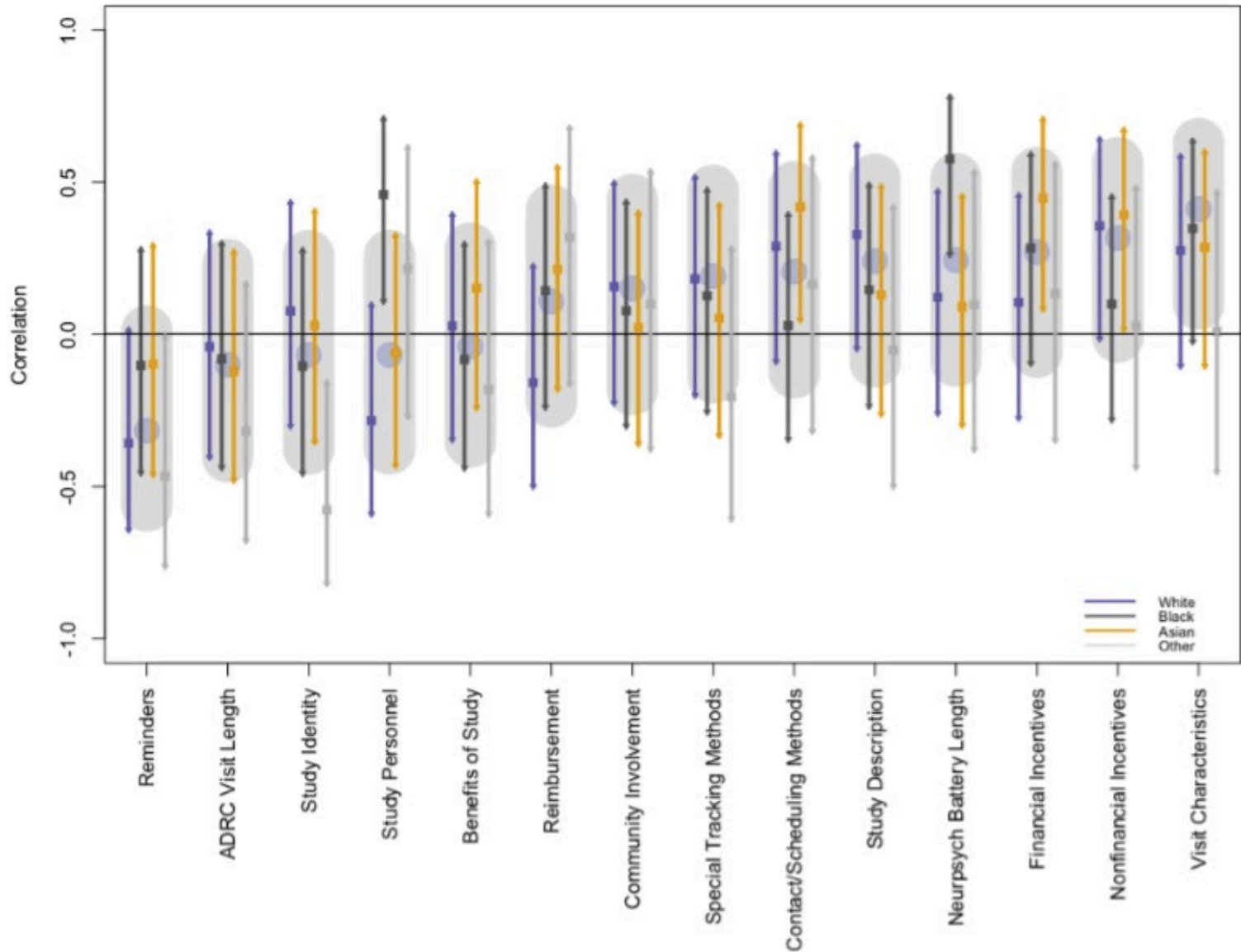
Correlations Between Strategies and Retention: Diagnostic Groups



Correlations Between Strategies and Retention: Partner Groups



Correlations Between Strategies and Retention: Racial Groups



Summary and Conclusions

- Centers consistently engage in retention strategies but specific tactics vary in rates of implementation
- Retention performance is associated with the number of total retention tactics
- Specific participants (impaired, non-white, lacking spouse) may be more challenging to retain
- Specific tactics (flexible visits, non-financial incentives) may be most impactful on retention

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Retention of participants in longitudinal studies of AD



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University of Pittsburgh

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Washington University in St. Louis



Josh Grill, PhD

University of California, Irvine

Study of longitudinal retention of participants in research studies of AD

- Identify perceived facilitators and barriers to longitudinal research participation
 - Phone survey of 440 AD participants, 240 study partners across 4 sites
 - Survey items: Perceived Research Burden Assessment (Lingler et al); Review of literature
 - Sub-group analyses are planned (younger, under represented minority)
- Develop, member check and pilot new guidelines to increase study retention

Status

- Participant data has been collected, is in the process of being cleaned and merged for NACC study; UC Irvine study has been funded and is underway.
- Study partner data collection is nearing completion for NACC study.
- Anticipated guideline for pilot test in 2019

Thank you & Questions:

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