

## RESEARCH ARTICLE

# Factors associated with attitudes toward research MRI in older Asian Americans

Karthik J Kota<sup>1,2</sup>  | Alice Dawson<sup>1,3</sup> | Julia Papas<sup>1,3</sup> | Victor Sotelo<sup>1,3</sup> | Guibin Su<sup>3</sup> | Mei-Ling Li<sup>3</sup> | Woowon Lee<sup>3</sup> | Jaunis Estervil<sup>3</sup> | Melissa Marquez<sup>3</sup> | Shromona Sarkar<sup>3</sup> | Lisa Lanza Lopez<sup>3</sup> | William T. Hu<sup>1,3</sup> 

<sup>1</sup>Departments of Neurology, Institute for Health, Health Care Policy, and Aging Research, Rutgers Biomedical and Health Sciences, New Brunswick, New Jersey, USA

<sup>2</sup>Departments of Medicine, Rutgers-Robert Wood Johnson Medical School, Institute for Health, Health Care Policy, and Aging Research, Rutgers Biomedical and Health Sciences, New Brunswick, New Jersey, USA

<sup>3</sup>Center for Healthy Aging, Institute for Health, Health Care Policy, and Aging Research, Rutgers Biomedical and Health Sciences, New Brunswick, New Jersey, USA

## Correspondence

William T. Hu, Rutgers Biomedical and Health Sciences, 112 Paterson Street, Room 462, New Brunswick, NJ 08901, USA.  
Email: [William.hu@rutgers.edu](mailto:William.hu@rutgers.edu)

## Funding information

NIH, Grant/Award Numbers: R24 AG063729, P30 AG059304

## Abstract

**INTRODUCTION:** South Asian (SA) and East Asian (EA) older adults represent the fastest-growing racial/ethnic groups of Americans at risk for dementia. While recruiting older SA adults into a brain health study, we encountered unexpected hesitancy toward structural brain magnetic resonance imaging (MRI) analysis and stigmatizing attitudes related to internal locus of control (LoC) for future dementia risks. We hypothesized that support for MRI-related research was influenced by these attitudes as well as personal MRI experience, perceived MRI safety, and concerns for personal risk for future dementia/stroke.

**METHODS:** We developed a brief cross-sectional survey to assess older adults' MRI experiences and perceptions, desire to learn of six incidental findings of increasing impact on health, and attitudes related to dementia (including LoC) and research participation. We recruited a convenience sample of 256 respondents (74% reporting as 50+) from the New Jersey/New York City area to complete the survey (offered in English, Chinese, Korean, and Spanish) and modeled the proportional odds (PO) for favorable attitudes toward research activities.

**RESULTS:** Seventy-seven SA and 84 EA respondents were analyzed alongside 95 White, Black, or Hispanic adults. White (PO = 2.54,  $p = 0.013$ ) and EA (PO = 2.14,  $p = 0.019$ ) respondents were both more likely than SA respondents to endorse healthy volunteers' participation in research, and the difference between White and SA respondents was mediated by the latter's greater internal LoC for dementia risks. EA respondents had more worries for future dementia/stroke than SA respondents ( $p = 0.006$ ) but still shared SA respondents' lower wish (measured by proportion of total) to learn of incidental MRI findings.

**DISCUSSION:** SA—and EA compared to SA—older adults had low desire to learn of incidental MRI findings but had different attitudes toward future dementia/stroke risks. A

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial-NoDerivs](https://creativecommons.org/licenses/by-nc-nd/4.0/) License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2024 The Authors. Alzheimer's & Dementia: Translational Research & Clinical Interventions published by Wiley Periodicals LLC on behalf of Alzheimer's Association.

culturally appropriate protocol to disclose incidental MRI findings may improve SA and EA participation in brain health research.

#### KEYWORDS

aged, Asian, clinical neurology, cognition, dementia, disclosure/ethics, East Asian, immigrants, incidental findings, MRI, neuroimaging, race/ethnicity, South Asian, surveys and questionnaires, informed consent/ethics

#### Highlights

- Older Asian Americans have limited interest in incidental findings on research MRI
- South Asians are most likely to attribute dementia to people's own behaviors
- South Asians' attitudes mediate lower support for healthy volunteers in research
- South and East Asians differ in dementia worries and research-related attitudes

## 1 | INTRODUCTION

Asian Americans represent the fastest-growing US racial group<sup>1</sup> and the fastest-growing group of adults over 65.<sup>1,2</sup> Asian Americans report ancestry from East Asia, the Indian Subcontinent (South Asia), and South East Asia; over half of older Asian Americans live in California, New York, Texas, New Jersey, and Washington.<sup>1</sup> US-based Asian immigrants differ from their Asia-based counterparts by educational attainment, socioeconomic status, and health behaviors.<sup>3</sup> Health record studies suggest older Asian Americans have lower dementia diagnosis prevalence than older non-Hispanic White (White) adults,<sup>4</sup> but whether this is from differences in dementia risk, detection, or stigma remains unclear.<sup>5</sup> This observation contradicts another: standardized dementia prevalence is comparable in Asia (5.63% to 7.15%, South vs. Southeast Asia), Europe (4.65% to 6.67%, Central vs. Western Europe), and North America (6.77%).<sup>6</sup> This difference could be from so-called healthy immigrant effects, but South Asian (SA) adults in North American studies have disproportionate atherosclerotic disease risks.<sup>7</sup> This suggests greater vascular than degenerative contribution to dementia among SA adults, an assumption complicated by varying genetic risks, acculturation effects,<sup>8</sup> and greater stroke mortality in Asian – compared to White – populations.<sup>9</sup> Increasing SA adult enrollment into biomarker-based memory and aging studies would improve this group's dementia prevention and diagnosis.

Structural brain MRI is a common clinical and research tool to detect cerebrovascular disease and neurodegeneration. Discussions on recruitment into research involving MRI have focused on safety, rather than acceptability to participants.<sup>10</sup> This is especially relevant in aging research, where participants face serial high-field or one-time ultra-high-field MRI analysis of increasing duration and complexity.<sup>11</sup> One study showed aggregated Asian American respondents were willing to undergo research brain MRI,<sup>12</sup> but less is known about disaggregated East Asian (EA) and SA adults' preferences. Limited literature suggests low knowledge of MRI's non-

radiation nature in China<sup>13</sup> and nocebo effects of overly clinical MRI reports in India.<sup>14</sup> How these factors affect Asian Americans' research participation is unexamined. Disclosure of incidental findings on brain MRI – identified in 1.7% to 4.3% of research scans<sup>15</sup> – also warrant discussion.<sup>16,17</sup> Mainstream US/UK protocols follow Western legal and ethical frameworks,<sup>17,18</sup> but these guidelines' cultural appropriateness may be more relevant in clinical than research settings.

While recruiting for a prospective memory and aging study in the New Jersey/New York City (NJ/NYC) area, we encountered significant concerns from potential SA participants regarding MRI. MRI is a broadly acceptable non-invasive examination in the US and UK, but prior studies did not include many older SA adults.<sup>19</sup> Based on meetings with SA community leaders, we hypothesized that older SA adults had greater internal health-related locus of control (LoC,<sup>20</sup> that is, future disease risks are influenced by one's own actions<sup>21</sup>) than older White adults who often wished to further reduce their future dementia risks through research participation.<sup>22</sup> However, other factors such as prior exposure to MRI (brain or body), perceived harm from MRI, concerns about one's own future dementia risks, and attitudes toward healthy people volunteering in medical research could also influence their decisions to participate in MRI-related research. To narrow down these possibilities for more culturally appropriate community engagement, our primary objective was to characterize these experiences and attitudes toward dementia, brain MRI, and research participation through a short survey. Because some of these factors may not be unique to older SA adults,<sup>23</sup> we also recruited older EA adults as a comparator group. This allowed us to determine whether disease- and safety-related attitudes differed between older SA and EA adults and whether these differences along racial/ethnic grouping-mediated differences in research-related attitudes.

Researchers have examined LoC among Asian immigrants to North America for 45 years,<sup>24</sup> but it remains uncertain whether the commonly used Multi-Dimensional Health Locus of Control scale<sup>25</sup> is culturally appropriate in SA populations. Thus, to assess disease- and

safety-related attitudes, we developed our survey using common statements from our meetings with SA community leaders, followed by principal component analysis (PCA) to minimize multiple comparisons of similar concepts. We hypothesized older SA adults to have lower self-perceived dementia risks and lower wish to discover incidental MRI findings than older White adults. If older SA adults did have lower self-perceived dementia risks, we would then test whether these attitudes mediated attitudes toward research-related attitudes.

## 2 | MATERIALS AND METHODS

### 2.1 | Consent statement

The anonymous MRI survey collected no protected health information, and the study was considered exempt human subject research by Advarra Institutional Review Board.

### 2.2 | Survey

Our cross-sectional survey on MRI research participation attitudes collected information on race/ethnicity (option to select from Hispanic, White, Black, EA [eg, Chinese, Korean], SA, Other with write-in space) and age (<50, 50 to 59, 60 to 69, 70 to 79, 80+); experience with any or brain MRI; belief about whether MRI emits radiation or causes cancer (yes, no, not sure); perceived prevalence of incidental brain MRI findings among people without neurological disorders (<5%, 5% to 10%, 15% to 25%, >50%), which may influence the wish to learn one's personal findings; desire to learn of six incidental MRI findings of increasing severity ("entirely benign"; "past injury, no longer threat"; "common findings, can improve health"; "unclear findings, need more testing"; "serious finding with treatment"; "serious finding with no treatments"); and 10 Likert-scale questions (1 = strongly disagree; 3 = neutral; 5 = strongly agree) on research and brain health attitudes, administered via paper ( $n = 156$ ) and online ( $n = 100$ ). Research-related questions were as follows: "Healthy people do not need to participate in medical research, because there is no direct benefit to them"; "After my name is removed from my brain scan, I am comfortable with the idea of scientists [who are not all physicians] I have never met examine the images." Brain health-related questions included internal LoC-associated dementia risk factors noted by SA adults ("A diet low in meat is effective in preventing Alzheimer's disease and dementia"; "Brain diseases like Alzheimer's and dementia only happen to people who don't regularly exercise their brains [eg, through reading];" "Only people with diabetes or strokes will develop dementia"), perceived MRI safety ("Putting a person in a strong magnetic field cannot cause long-term physical harm"; "Putting a person in a strong magnetic field cannot cause long-term mental harm"), forgetfulness ("Forgetting conversations and appointments I don't care about is a normal part of aging"), and concerns about personal future brain health ("I am afraid that I might have dementia or strokes in the future"). Stroke and dementia were unseparated since potential participants frequently mentioned both when discussing brain health and because

### Research In Context

- 1. Systematic review:** Brain magnetic resonance imaging (MRI) is routine in many memory and aging studies consisting of mostly White participants, but little is known about South Asian (SA) and East Asian (EA) older adults' attitudes toward research brain imaging. White participants' preference for full disclosure has supported policies related to incidental findings on MRI, while neuroimaging studies in Asia have variable models of disclosure.
- 2. Interpretation:** SA versus White older adults in New Jersey/New York City have lower desire to learn of incidental MRI findings. Different beliefs about SA and EA older adults' own dementia risks – independent of experience with MRI and perceived safety – influence attitudes toward research participation.
- 3. Future directions:** Recruitment of SA and EA older adults into memory and aging studies needs to better account for cultural factors related to disease origin and risks, and a participant-centered disclosure model for incidental findings should be tested to improve trust.

of the World Stroke Organization's proclamation for joint prevention of stroke and preventable dementia.<sup>26</sup> Finally, we added a dementia-related stigma statement ("People with dementia should be separated from society for their and our safety") for its relationship to research participation.<sup>27</sup> Since survey-based hypothetical willingness to participate in research has been criticized, we did not include a question on research participation willingness.<sup>28</sup>

Surveys were translated into Chinese, Korean, and Spanish through forward and backward translation and then proofed by fluent bilingual project scientists. In contrast, we note SA adults to come from heterogeneous geographic, cultural, and linguistic backgrounds even within each census-designated ethnic grouping. Asian Indian (~85%) and Pakistani (~5%) Americans represent the largest ethnic groups in NJ. Whereas 5% to 10% of the population in India speak English, 91% of Asian Indian or Pakistani NJ adults (including 72% of those 65 years of age or older) speak English well (15%), very well (62%), or exclusively (14%).<sup>29</sup> In consultation with local SA community groups prior to the study, we thus elected to not translate our survey into SA languages because of the group's much higher English fluency than other groups, the large number of native tongues, and insufficient language expertise on the research team to equitably represent sufficient number of native tongues to not alienate potential participants. This decision reflects our older SA community members' preference for completing surveys in English even when research staff spoke Hindi or Gujarati, and is further supported by national surveys conducted only in English or Spanish that nevertheless elucidated health behaviors and cultural practices in SA communities.<sup>30,31</sup> The survey was piloted

(Supplementary Methods) before the final version was administered, and its completion took 3 to 5 minutes.

## 2.3 | Participants

A convenience sample was recruited between August 2022 and January 2023 from Rutgers General Internal Medicine Clinic ( $n = 8$ ), Rutgers Neurology Clinic ( $n = 37$ ), aging and health disparities research community events ( $n = 64$ ), research registry solicitation ( $n = 39$ ), and word-of-mouth referrals ( $n = 108$ ). Participants were eligible if they could read and respond in English, Chinese (Simplified or Traditional), Korean, or Spanish. We approached participants appearing age 50 or older but did not exclude respondents subsequently reporting age <50. We told respondents the study's purpose was understanding "attitudes and knowledge about MRI and dementia." Participants were not offered incentives.

## 2.4 | Statistical analysis

All statistical analysis was conducted in SPSS 28.0 (IBM-SPSS, Armonk, NY, USA). Differences between groups were analyzed by chi-squared tests for categorical variables (eg, race/ethnicity, source of recruitment) or regression analysis (eg, ordinal for healthy people volunteerism beliefs, linear for attitude-related PC scores). Chinese and Korean respondents had similar MRI experience and attitudes (Supplementary Methods), and they were thus analyzed together as one EA group. Instead of using the White population as the reference group, we used a SA reference to identify racial/ethnic characteristics that differed from our population of interest. The sample size was sufficiently powered for PCA and regression analyses (Supplementary Methods).

Responses to the two Likert-scale questions on research participation were analyzed as dependent variables in ordinal regression models. Models involving five response categories for healthy people as research participants met the parallel regression assumption. Models involving sharing de-identified MRI did not meet the parallel regression assumption with five categories but did with three categories (disagree, neutral, agree), possibly reflecting the effects of extreme answers. Ordinal outcomes involving these three categories were thus used for sharing de-identified MRI. PCA of the eight Likert-scale questions for brain health attitudes was performed due to potential commonality (eg, long-term physical and mental risks of MRI), and principal component (PC) scores were analyzed across racial/ethnic groups using analysis of covariance, adjusting for age categories. Those PCs that differed significantly according to race/ethnicity were entered into later mediation models.

In logistic (eg, desire to learn of an incidental MRI finding type) and ordinal (eg, attitudes toward healthy people as research participants) regression models, odds ratio (OR) and proportional odds (PO) are reported with 95% confidence interval (CI). Race/ethnicity, age, recruitment site, prior MRI exposure, and attitude-related PC scores

were entered into each logistic or ordinal regression model using the forward stepwise approach.

For factors that differed between SA and non-SA groups, we further examined the relationships among demographic factors (race/ethnicity, age), prior experience with MRI, brain health attitudes, and research-related attitudes using *post hoc* regression-based mediation models.<sup>32</sup> Ordinal regression analysis was first performed between the independent variable (race/ethnicity) and the dependent outcome variable (research-related attitudes). Significant relationships were first identified, and a possible mediator that differed according to the independent variable (race/ethnicity, by linear regression given the scalar nature of possible mediators) was introduced into the ordinal/logistic regression model. If the possible mediator is associated with the outcome variable and the introduction of the possible mediator reduced the association between the independent and outcome variables, we consider the introduced term mediator. The full model also included age, recruitment source, and prior MRI exposure as covariates.

## 3 | RESULTS

### 3.1 | Demographics, MRI experience, and knowledge

Among 256 respondents, 33%, 30%, 21%, 7%, and 6% identified as EA, SA, White, Black, and Hispanic, respectively. Sixty-six (26%) reported age <50 (Table 1), and Hispanic respondents were younger than SA respondents ( $p = .020$ ). White respondents were more likely recruited via registries and word-of-mouth referrals than other respondents (100% vs 67%,  $p < .001$ ). Respondents were otherwise similar in age and recruitment source.

Most respondents overestimated MRI brain incidental finding prevalence (76%), while a minority believed MRI could increase cancer risks (12.5%); there was no difference by race/ethnicity ( $p = .320$  and  $p = 0.226$ ). Compared to SA respondents, White respondents were more likely to have had any MRI (OR 2.91, 95% CI: 1.29 to 6.58, adjusting for age and referral source; Table 1) or brain MRI (OR 3.82, 95% CI: 2.20 to 6.62; Table 1).

### 3.2 | Incidental findings on brain MRI

Most respondents (229/249, 92%) wished to learn about one or more incidental findings on their own brain MRI. SA and EA respondents expressed the lowest, while White respondents expressed the highest, desire to learn of six incidental brain MRI findings (Figure 1). Relative to SA respondents, wishing to be informed of more incidental brain MRI findings was associated with White race (PO = 3.60, 95% CI: 1.70 to 6.82,  $p < .001$ ) but not EA ethnicity. Age, recruitment site, and prior MRI experience had no influence on desire.

Of note, 35% of respondents did not wish to learn of serious MRI findings with effective treatments, and 52% did not wish to learn of uncertain findings requiring further testing.

**TABLE 1** Survey respondents' demographic information, MRI experience, wish to learn of incidental MRI finding, and research-related attitudes

	Total East Asian (n = 84)	South Asian (n = 77)	White (n = 54)	Black (n = 19)	Hispanic (n = 15)	Other (n = 7)
Age						
<50	22	13	14	5	7*	5
50 to 59	14	7	10	3	0	0
60 to 69	25	35	16	2	6	1
70 to 79	18	17	11	4	1	1
80+	4	5	3	4	0	0
Had any prior MRI (%)	42 (50%)	39 (51%)	39 (72%)	13 (68%)	9 (60%)	3 (43%)
Had a prior brain MRI (%)	23 (27%)	16 (21%)	26 (48%)	4 (21%)	5 (33%)	2 (29%)
Recruitment site						
Clinic	3	0	23	7	9	3
Events	34	18	0	11	1	0
Registry	35	2	7	0	3	0
Referrals	12	57	24	1	2	4
Entirely benign	24 (29%)	27 (35%)	29 (54%)	8 (42%)	12 (80%)	4 (57%)
Past injury, no longer threat	22 (26%)	29 (38%)	31 (57%)	8 (42%)	7 (47%)	4 (57%)
Common findings, can improve health	42 (50%)	45 (58%)	33 (61%)	10 (53%)	9 (60%)	5 (71%)
Unclear findings, need more testing	29 (35%)	33 (43%)	39 (72%)	8 (42%)	10 (67%)	4 (57%)
Serious finding with treatment	50 (59%)	44 (57%)	43 (80%)	12 (63%)	12 (80%)	5 (71%)
Serious finding with no treatments	25 (30%)	27 (35%)	35 (65%)	8 (42%)	7 (47%)	4 (57%)
Research Q1	n = 78	n = 70	n = 47	n = 14	n = 15	n = 7
Strongly agree	7	11	1	0	2	0
Agree	3	6	3	2	1	1
Neutral	11	14	7	4	2	1
Disagree	12	12	10	3	7	1
Strongly disagree	45	27	26	5	3	4
Research Q2	n = 78	n = 68	n = 46	n = 14	n = 15	n = 7
Strongly agree	32	21	18	0	6	1
Agree	14	10	17	2	1	3
Neutral	15	18	8	4	7	0
Disagree	9	10	0	3	0	1
Strongly disagree	8	9	3	5	1	2

Note: Median age category in each racial/ethnic group was 60 to 69 except for Hispanic (50 to 59) and Other (<50). (\* One Hispanic respondent did not provide age). Self-reported East Asian ethnic groups are further explored in Table S1.

Abbreviation: MRI, magnetic resonance imaging.

### 3.3 | Attitudes toward research participation, dementia, and MRI

Two hundred eight participants (81%) provided complete responses to the 10 Likert-scale questions, with 25 (10%) omitting over half of the brain health attitude questions. Compared to non-completers, participants who completed attitude questions were less likely from a clinical referral site (16 vs 32%,  $p = .01$ ) or Black (5% vs 22%,  $p < .001$ ); they were otherwise similar in age, past MRI experience, and research-related attitudes.

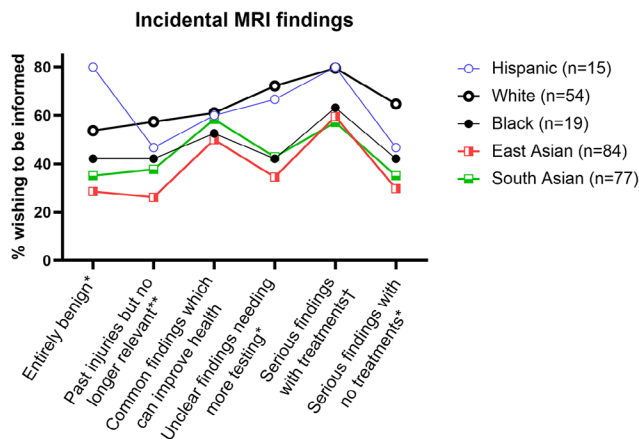
One hundred thirty-nine (67%) disagreed that "Healthy people do not need to participate in medical research, because there is no direct benefit to them" (Table 1, Research Q1), possibly reflecting the cohort's convenience nature. Similarly, 115 (55%) agreed that "After my name is removed from my brain scan, I am comfortable with the idea of scientists (who are not all physicians) I have never met examine the images" (Table 1, Research Q2). Compared to SA respondents, White respondents were more likely to believe healthy people should volunteer (PO = 2.54, 95% CI: 1.22 to 5.32,  $p = .013$ ) and share de-identified MRI for research (PO = 2.33, 95% CI: 1.45 to 3.74,  $p < .001$ ; adjusting for age). EA



**TABLE 2** Principal component analysis of attitudes related to brain health (loading scores > 0.100 shown)

	PC1	PC2	PC3
A strong magnetic field cannot cause long-term mental harm	0.925		
A strong magnetic field cannot cause long-term physical harm	0.921	0.103	
Diet low in meat prevents Alzheimer's and dementia	0.293	0.185	0.235
Brain diseases happen to people who don't exercise their brains		0.829	0.113
People with dementia should be separated from society		0.743	
Only people with diabetes or strokes develop dementia		0.664	
I am afraid that I might have future dementia or strokes			0.834
Forgetting things that are not important to me is normal aging	0.102	0.149	0.720

Note: PC1 related to long-term MRI safety, PC2 related to internal locus of control (LoC) for developing dementia, and PC3 related to respondents' own worries for future dementia/stroke risks.



**FIGURE 1** Proportion of respondents who wish to be informed of incidental MRI findings by types of finding (x-axis) and race/ethnicity. \* $p \leq .001$ ; \*\* $p < .01$ ; † $p < .05$

respondents also were more likely than SA respondents to believe healthy people should volunteer (PO = 2.14, 95% CI: 1.13 to 4.05,  $p = .019$ ).

For the remaining brain health attitudes questions (Figure 2), PCA identified three PCs (Table 2): long-term MRI safety (PC1; higher score means belief that MRI is safe), internal LoC for developing dementia (PC2, higher score means greater self-control of future dementia risks), and respondents' worries over future dementia/stroke risks (PC3; higher score means greater worry). Compared to SA respondents, White respondents had lower internal LoC for dementia ( $p = .043$ ), and EA ( $p = .006$ ) and Hispanic ( $p = .019$ ) respondents had greater worries over future dementia/stroke risks. Respondents  $\geq 50$  believed in greater internal LoC than those  $< 50$  ( $p = .026$ ); there was otherwise no difference among groups  $\geq 50$ .

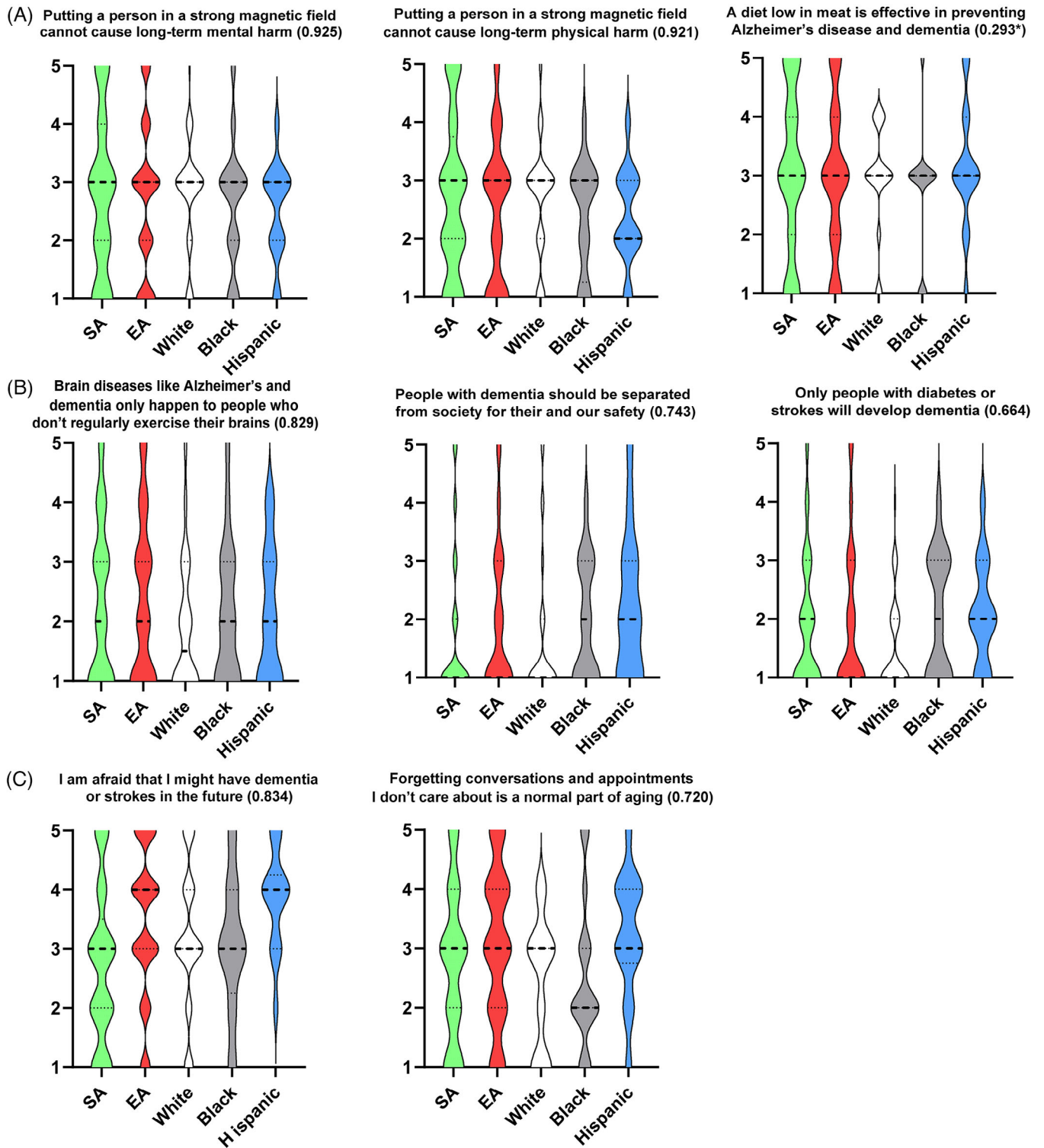
### 3.4 | Factors associated with favorable research attitudes

We next analyzed whether the three PCs mediated research-related attitude differences between SA and non-SA respondents.<sup>27</sup> Com-

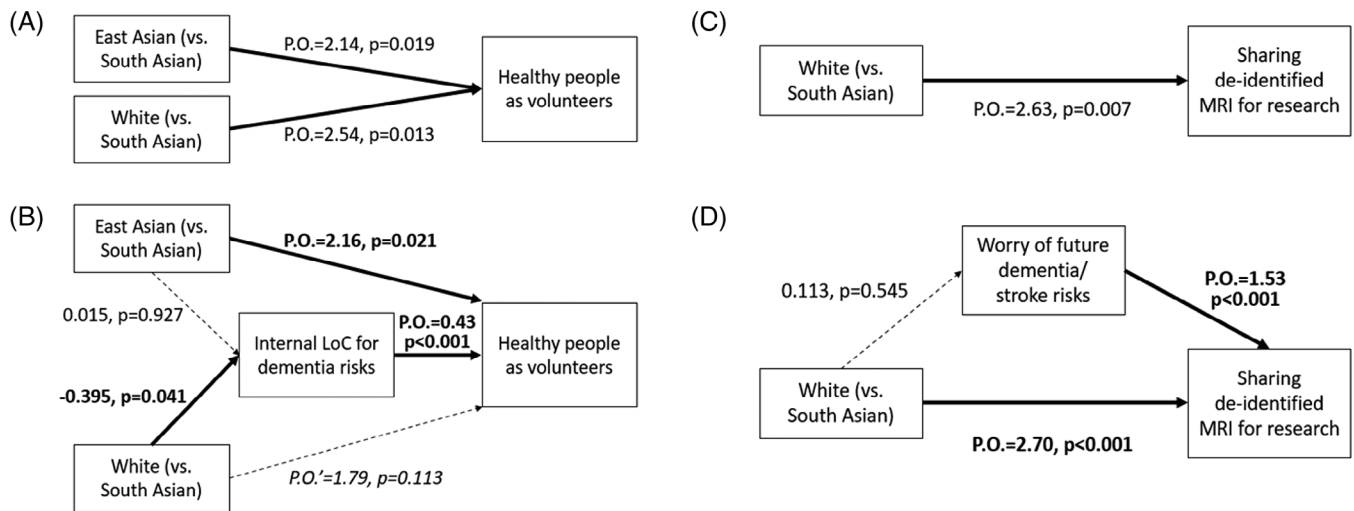
pared to SA respondents, both EA (PO = 2.14, 95% CI: 1.13 to 4.05,  $p = .019$ ) and White (PO = 2.54, 95% CI: 1.22 to 5.32,  $p = .013$ ) respondents had stronger belief that healthy people should volunteer for research (Figure 3A). Internal LoC was associated with reduced support for healthy people as research volunteers (PO = 0.43, 95% CI: 0.32 to 0.56,  $p < .001$ ), and introducing internal LoC diminished the difference between SA and White respondents but not between SA and EA respondents (Figure 3B). We interpreted this as support for LoC mediating the difference between SA and White respondents, but not between the two Asian groups. In contrast, greater worry for future dementia/strokes was associated with more willingness to share de-identified MRI for research but could not account for the greater willingness in White than SA respondents (Figure 3C,D).

### 3.5 | Factors associated with disclosure of incidental MRI findings

Finally, we assessed whether MRI experience and attitudes related to dementia and research explained differences in desire to learn of incidental MRI findings (past injury, unclear findings, and serious findings with or without effective treatments) between racial/ethnic groups (Figure 1). Age 70+ was associated with a lower desire to learn of serious incidental findings with (OR = 0.77, 95% CI: 0.65 to 0.92,  $p = .005$ ) or without effective treatment (OR = 0.70, 95% CI: 0.59 to 0.84,  $p < .001$ ), while age 60 to 69 was only associated with lower desire for serious findings without treatment (OR = 0.76, 95% CI: 0.64 to 0.89,  $p = .001$ ; Table 3). Worry over future dementia/stroke risks was associated with a slightly greater desire to learn of all findings except serious findings without treatment (OR = 1.08 to 1.09,  $p < .05$ ), while perceiving MRI as safe was associated with slightly greater desire to learn all findings except serious findings with effective treatments (OR = 1.07 to 1.10,  $p < .05$ ). Recruitment from the community was associated with a greater desire to learn about serious findings with treatment (OR = 1.27, 95% CI: 1.09 to 1.49,  $p = .003$ ). However, even after adjusting for age group, recruitment site, worry of future dementia/stroke, and perceived MRI safety, White respondents – compared to SA respondents – still had a greater desire to learn all MRI findings: past injury



**FIGURE 2** Attitudes related to brain health according to race/ethnicity and PCA. PC1 primarily involved long-term MRI safety (A, \*low meat diet question had low loading overall but highest loading on PC1); PC2 involved internal LoC for developing dementia (B); PC3 involved worries for future dementia/stroke risks (C)



**FIGURE 3** Mediation analysis for whether healthy people should volunteer in research (strongly disagree, disagree, neutral, agree, strongly agree) and sharing de-identified MRI for research (disagree, neutral, agree). Attitudes toward research participation were analyzed without (A, C) or with (B, D) the inclusion of attitudes related to brain health (internal LoC for dementia risks, fear for future dementia/stroke risks) as a mediator for difference between SA and other racial/ethnic respondents. PO, proportional odds

**TABLE 3** Factors associated with desire to learn of different incidental MRI findings

	Past injury	Unclear findings	Serious findings with effective treatment	Serious findings with no effective treatment
<b>Race</b>				
South Asian	Reference	Reference	Reference	Reference
Hispanic	0.99 (0.74, 1.32), $p = .940$	1.27 (0.96, 1.69), $p = .096$	1.16 (0.86 to 1.59), $p = .318$	0.99 (0.75 to 1.31), $p = .947$
<b>White</b>	<b>1.24 (1.04 to 1.48), <math>p = .017</math></b>	<b>1.44 (1.21, 1.73), <math>p &lt; .001</math></b>	<b>1.25 (1.04 to 1.51), <math>p = .018</math></b>	<b>1.37 (1.15 to 1.62), <math>p &lt; .001</math></b>
Black	1.05 (0.78 to 1.42), $p = .751$	1.07 (0.79, 1.44), $p = .660$	1.10 (0.80 to 1.51), $p = .541$	1.02 (0.76 to 1.37), $p = .893$
East Asian	<b>0.84 (0.72 to 0.99), <math>p = .037</math></b>	0.93 (0.80, 1.10), $p = .409$	1.00 (0.85 to 1.17), $p = .986$	0.90 (0.77 to 1.05), $p = .180$
<b>Age</b>				
<50	Reference	N.S.	Reference	Reference
50-59	1.08 (0.88 to 1.34), $p = .451$		0.94 (0.77 to 1.16), $p = .572$	0.94 (0.76 to 1.16), $p = .555$
<b>60-69</b>	0.96 (0.81 to 1.14), $p = .650$		0.86 (0.73 to 1.02), $p = .078$	<b>0.76 (0.64 to 0.89), <math>p = .001</math></b>
70+	0.83 (0.69 to 1.00), $p = .052$		<b>0.77 (0.65-0.92), <math>p = .005</math></b>	<b>0.70 (0.59 to 0.84), <math>p &lt; .001</math></b>
<b>Recruitment site</b>				
Events	N.S.	N.S.	Reference	N.S.
<b>Community contacts</b>			<b>1.27 (1.09 to 1.49), <math>p = .003</math></b>	
Clinic			1.14 (0.90 to 1.45), $p = .261$	
<b>Worry of future dementia/stroke</b>	<b>1.09 (1.02 to 1.16), <math>p = .010</math></b>	<b>1.08 (1.01, 1.15), <math>p = .025</math></b>	<b>1.08 (1.01-1.15), <math>p = .024</math></b>	1.06 (1.00 to 1.13), $p = .058$
<b>MRI safe</b>	<b>1.09 (1.02 to 1.16), <math>p = .012</math></b>	<b>1.07 (1.01, 1.14), <math>p = .034</math></b>	N.S.	<b>1.10 (1.03 to 1.17), <math>p = .003</math></b>

Note: Values shown are odds ratio with 95% CI and  $p$ -values. Model for entirely benign findings not shown as it was not influenced by any factor other than racial/ethnic category, and factors not significantly associated with any outcomes (LoC, past MRI experience) also not shown.

Abbreviation: MRI, magnetic resonance imaging.

(OR = 1.24, 95% CI: 1.04 to 1.48,  $p = .017$ ), unclear findings (OR = 1.44, 95% CI: 1.21 to 1.73,  $p < .001$ ), and serious findings with (OR = 1.25, 95% CI: 1.04 to 1.51,  $p = .018$ ) and without effective treatments (OR = 1.37, 95% CI: 1.15 to 1.62,  $p < .001$ ; Table 3).

## 4 | DISCUSSION

Here we surveyed older Asian and non-Asian Americans on aging brain health research participation attitudes. Older SA respondents



had less interest in learning about incidental MRI findings than older White respondents, even after adjusting for dementia/safety-related attitudes, prior MRI experience, and recruitment site. Attitude differences related to LoC did mediate SA respondents' lower support for healthy people as research volunteers, but no attitude differences could account for their lower desire to share de-identified MRI for research purposes. Further studies are necessary to identify broader cultural and social factors underlying low interest for learning MRI findings and sharing de-identified MRI.

Aging studies involving SA<sup>33</sup> adults are generating epidemiological insight into psychosocial factors influencing brain health; however, neuroimaging data – including willingness to undergo brain imaging – are lacking.<sup>34</sup> With exceptions,<sup>35,36</sup> cross-racial/ethnic studies on dementia attitudes (excluding those assessing only one racial/ethnic group) have historically recruited mostly White, Black, and Hispanic participants. We did not find a difference in MRI safety perceptions among racial/ethnic groups, but we did find greater belief in internal LoC for dementia risks among SA respondents. Older SA adults' perceived self-efficacy<sup>20</sup> thus contrasts with older EA respondents' greater worry for future dementia/stroke risks.<sup>37,38</sup> If validated in a larger multiethnic Asian American population, this distinction between “I don't need to know” associated with low self-perceived risks among SA and “I don't want to know” associated with fear among EA adults may have significant implications for Asian American recruitment into memory and aging studies. This can be especially true for investigations involving genetic risk disclosure, greater invasiveness (eg, cerebrospinal fluid markers), very low dose radiation (positron emission tomography), and experimental therapeutics. These attitude differences thus reinforce the need to disaggregate different Asian American subgroups when conducting health-related research. At the same time, Asian American immigrants are not just displaced Asians due to influences by immigration history and surrounding (“host”) societal values. While we are not aware of a study directly comparing US SA or EA adults' dementia-related attitudes with their counterparts in corresponding countries of origin, one study found dementia-related worries to correlate with knowledge among older Chinese adults living in Australia, but not China.<sup>39</sup> Strategies leveraging culture/ethnicity-specific understanding of dementia-related LoC and fear thus have the potential to overcome attitudinal barriers to research participation and improve health equity.

Variable desire to learn of incidental MRI findings among racial/ethnic groups underscores the urgency for thoughtful flexibility. Incidental finding disclosure standards in US biomedical research abide by “actionability.”<sup>18</sup> Actionability is determined via well-established medical actions, patient/participant-initiated health-related actions, and life-plan decisions.<sup>40</sup> Challenges in a one-size-fits-all brain imaging disclosure strategy were noted as early as 2002.<sup>10</sup> We could find no culturally sensitive algorithm to determine if, how, and how many research MRI incidental findings should be disclosed to Asian adults living in the US or UK; Chinese aging studies' practices vary, regardless of incidental finding prevalence.<sup>41,42</sup> In genomic information disclosure, multiple models exist, balancing truth telling and doing no harm.<sup>43</sup> An “ask-tell-ask” approach might be appropriate in MRI

research involving cognitively normal volunteers,<sup>44</sup> but stakeholder focus groups,<sup>45</sup> improving health literacy,<sup>46</sup> and incidental finding committees<sup>47</sup> are all potential, though untested, solutions in multi-cultural settings. Possibly, exposure to trustworthy medical research and asymptomatic disease detection may shift participant preference for learning incidental findings. Thus, picking a single convenient model may underestimate older Asian adults' cultural adaptability and asymmetrically place informed consent burdens on research participants, while a flexible or progressive disclosure model may be preferable even if it requires further evidence generation and refinement.

This study's sample size is similar to previous ones analyzing incidental MRI findings disclosure,<sup>17,48</sup> but our convenience sample has several limitations. Not unlike other memory and aging studies, most minoritized participants were recruited through specialized outreach efforts. This convenience sampling thus increased our risk of type I error. We did not assess acculturation, as existing acculturation scales have limited generalizability across racial/ethnic groups. We also fell short in convergent validity, as a strength of the survey was its community-sourced input. Importantly, we cannot explain different disclosure wishes between SA and White respondents despite assessing several attitude-related domains, nor why EA respondents had greater support for healthy people as research volunteers than SA respondents. We limited our survey's length to one page based on Asian older adults' hesitancy in research participation, limiting collection of more detailed demographics (eg, gender), sociobehavioral data (eg, household income, neighborhood disadvantage), and attitudes. We did not include years of education, as this variable is higher in Asian Americans than the general American public<sup>1</sup>; additionally, there is no method to disentangle often colinear years of education, quality of international versus US education, and immigrant status. Other attitude influencers include gendered role (traditional and US-based), socioeconomic status (challenging to assess in both retired persons and immigrants), immigration history (age at immigration, years living in US), altruism, discrimination (including caste), prior employment in medicine/medical research, acculturation, LoC, and personality traits. The concentration of Asian adults in NJ/NYC made this study feasible, but findings may not generalize to other US regions. Using more than one language for surveys could impact results by cultural differences for which we did not account. We performed PCA to derive attitude-related PC scores but did not assess Likert-scale questions' reliability over time. Finally, while Hispanic and Black respondents showed potentially distinguishing trends, they – and people reporting mixed or other race/ethnicity – were too few to explore potential causes.

In conclusion, we found similar incidental MRI finding preferences between SA and EA adults despite different support for research participation, internal LoC for dementia risks, and future dementia/stroke worries. We thus caution researchers against generalizing the linkage between perceptions and behaviors from one ethnic group to another, and call for more flexible – potentially individual-based – tailoring of incidental finding disclosure in MRI-related research.

## ACKNOWLEDGMENTS

We thank the South Asian Total Health Initiative and RWJBarnabas Health Chinese Medical Program for support in engaging participants. This work was supported by National Institutes of Health (NIH) R24 AG063729, NIH P30 AG059304, Rutgers Center for Advanced Human Brain Imaging Research, and Rutgers Biomedical and Health Sciences.

## CONFLICTS OF INTEREST STATEMENT

WTH has patents on cerebrospinal fluid-based diagnosis of frontotemporal lobar degeneration with TPD-43 immunoreactive physiology (FTLD-TDP), prognosis of mild cognitive impairment due to Alzheimer's disease, and prognosis of spinal muscular atrophy treatment; has consulted for Biogen, Fujirebio Diagnostics, and Roche. KK, AD, JP, VS, GS, ML, WL, JE, MM, SS, and LL have no disclosures. Author disclosures are available in the [Supporting Information](#).

## ORCID

Karthik J Kota  <https://orcid.org/0000-0001-5012-7382>

William T. Hu  <https://orcid.org/0000-0003-4862-6777>

## REFERENCES

- Budiman A, Ruiz NG. *Key facts about Asian Americans, a diverse and growing population*. Pew Research Center, 2021.
- [dataset] Bureau USC. S0103 | *Population 65 years and over in the United States*. 2020 ed: United States Census Bureau, 2020.
- Lee J, Zhou M. *The Asian American achievement paradox*. Russell Sage Foundation, 2015.
- Mayeda ER, Glymour MM, Quesenberry CP, Jr., Whitmer RA. Heterogeneity in 14-year dementia incidence between Asian american subgroups. *Alzheimer Dis Assoc Disord*. 2017;31:181-186.
- Lee S, Kim D, Lee H. Examine race/ethnicity disparities in perception, intention, and screening of dementia in a community setting: scoping review. *Int J Environ Res Public Health*. 2022;19(14):8865.
- Prince M, Wimo A, Guerchet M, Ali GC, Wu YT, Prina M. The global impact of dementia-an analysis of prevalence, incidence, cost and trends. *World Alzheimer's Report*. Alzheimer's Disease International, 2015.
- Volgman AS, Palaniappan LS, Aggarwal NT, et al. Atherosclerotic cardiovascular disease in south Asians in the United States: epidemiology, risk factors, and treatments: a scientific statement from the American heart association. *Circulation*. 2018;138:e1-e34.
- Needham BL, Mukherjee B, Bagchi P, et al. Acculturation strategies among south Asian immigrants: the mediators of atherosclerosis in South Asians Living in America (MASALA) study. *J Immigr Minor Health*. 2017;19:373-380.
- Jose PO, Frank AT, Kapphahn KI, et al. Cardiovascular disease mortality in Asian Americans. *J Am Coll Cardiol*. 2014;64:2486-2494.
- Kulynych J. Legal and ethical issues in neuroimaging research: human subjects protection, medical privacy, and the public communication of research results. *Brain Cogn*. 2002;50:345-357.
- Guo H, Siu W, D'Arcy RC, et al. MRI assessment of whole-brain structural changes in aging. *Clin Interv Aging*. 2017;12:1251-1270.
- Salazar CR, Hoang D, Gillen DL, Grill JD. Racial and ethnic differences in older adults' willingness to be contacted about Alzheimer's disease research participation. *Alzheimers Dement (N Y)*. 2020;6:e12023.
- Sin HK, Wong CS, Huang B, Yiu KL, Wong WL, Chu YC. Assessing local patients' knowledge and awareness of radiation dose and risks associated with medical imaging: a questionnaire study. *J Med Imaging Radiat Oncol*. 2013;57:38-44.
- Rajasekaran S, Dilip Chand Raja S, Pushpa BT, Ananda KB, Ajoy Prasad S, Rishi MK. The catastrophization effects of an MRI report on the patient and surgeon and the benefits of 'clinical reporting': results from an RCT and blinded trials. *Eur Spine J*. 2021;30:2069-2081.
- Morris Z, Whiteley WN, Longstreth WT, Jr., et al. Incidental findings on brain magnetic resonance imaging: systematic review and meta-analysis. *BMJ*. 2009;339:b3016.
- Hayward R. VOMIT (victims of modern imaging technology)—an acronym for our times. *BMJ*. 2003;326:1273.
- Phillips JP, Cole C, Gluck JP, et al. Stakeholder opinions and ethical perspectives support complete disclosure of incidental findings in MRI research. *Ethics Behav*. 2015;25:332-350.
- Office of Human Research Protections. Attachment F—Recommendations on reporting incidental findings. In: *Services US Department of Health and Human Services*, editor. 2017.
- Puyol-Anton E, Ruijsink B, Mariscal Harana J, et al. Fairness in cardiac magnetic resonance imaging: assessing sex and racial bias in deep learning-based segmentation. *Front Cardiovasc Med*. 2022;9:859310.
- Vlaar EM, Nierkens V, Nicolaou M, Middelkoop BJ, Stronks K, van Valkengoed IG. Risk perception is not associated with attendance at a preventive intervention for type 2 diabetes mellitus among South Asians at risk of diabetes. *Public Health Nutr*. 2015;18:1109-1118.
- Kesavayuth D, Poyago-Theotoky J, Tran DB, Zikos V. Locus of control, health and healthcare utilization. *Econ Model*. 2020;86:227-238.
- Grill JD, Karlawish J, Elashoff D, Vickrey BG. Risk disclosure and preclinical Alzheimer's disease clinical trial enrollment. *Alzheimers Dement*. 2013;9:356-359. e1.
- Liang J, Jang Y, Aranda MP. Stigmatising beliefs about Alzheimer's disease: findings from the Asian American quality of life survey. *Health Soc Care Community*. 2021;29:1483-1490.
- Stuart IR, Murgatroyd D, Denmark FL. Perceptual style, locus of control and personality variables among East Indians and blacks in Trinidad. *Int J Soc Psychiatry*. 1978;24:26-32.
- Grover S, Dua D. Hindi translation and validation of scales for subjective well-being, locus of control and spiritual well-being. *Indian J Psychol Med*. 2021;43:508-515.
- Hachinski V. Brain health—curbing stroke, heart disease, and dementia: the 2020 Wartenberg lecture. *Neurology*. 2021;97:273-279.
- Bardach SH, Kent S, Jicha GA. Alzheimer disease worries, fears, and stigma and their relationship to genetic and interventional research engagement. *Alzheimer Dis Assoc Disord*. 2021;35:75-79.
- Chu SH, Kim EJ, Jeong SH, Park GL. Factors associated with willingness to participate in clinical trials: a nationwide survey study. *BMC Public Health*. 2015;15:10.
- [dataset] American Community Survey. 2020 ACS 1-year public use microdata sample with experimental weights. 03/31/2022 ed: United States Census Bureau, 2022.
- Visaria A, Islam S, Polamarasetti P, et al. Hypertension, diabetes, and corresponding annual clinical testing utilization: comparison between Asian Indians and other races/ethnicities. *Prev Med*. 2021;153:106761.
- Kaushal N, Muchomba FM. Missing time with parents: son preference among Asians in the United States. *J Popul Econ*. 2018;31:397-427.
- Baron RM, Kenny DA. The moderator-mediator variable distinction in social psychological research: conceptual, strategic, and statistical considerations. *J Pers Soc Psychol*. 1986;51:1173-1182.
- Kanaya AM, Kandula N, Herrington D, et al. Mediators of atherosclerosis in South Asians Living in America (MASALA) study: objectives, methods, and cohort description. *Clin Cardiol*. 2013;36:713-720.
- Lockhart SN, Schaich CL, Craft S, et al. Associations among vascular risk factors, neuroimaging biomarkers, and cognition: preliminary analyses from the Multi-Ethnic Study of Atherosclerosis (MESA). *Alzheimers Dement*. 2022;18:551-560.
- Suzuki R, Goebert D, Ahmed I, Lu B. Folk and biological perceptions of dementia among Asian ethnic minorities in Hawaii. *Am J Geriatr Psychiatry*. 2015;23:589-595.

36. Zhai S, Kim B, Li J, et al. Perceptions and beliefs of memory loss and dementia among Korean, Samoan, Cambodian, and Chinese older adults: a cross-cultural qualitative study. *J Gerontol Nurs.* 2022;48:40-48.
37. Gray HL, Jimenez DE, Cucciare MA, Tong HQ, Gallagher-Thompson D. Ethnic differences in beliefs regarding Alzheimer disease among dementia family caregivers. *Am J Geriatr Psychiatry.* 2009;17:925-933.
38. Lee SE, Lee HY, Diwan S. What do Korean American immigrants know about Alzheimer's disease (AD)? The impact of acculturation and exposure to the disease on AD knowledge. *Int J Geriatr Psychiatry.* 2010;25:66-73.
39. Zhao M, Lv X, Lin X, et al. Dementia knowledge and associated factors among older Chinese adults: a cross-national comparison between Melbourne and Beijing. *Int Psychogeriatr.* 2021;33:1057-1067.
40. Moret C, Mauron A, Fokstuen S, Makrythanasis P, Hurst SA. Defining categories of actionability for secondary findings in next-generation sequencing. *J Med Ethics.* 2017;43:346-349.
41. Li S, Fang F, Cui M, et al. Incidental findings on brain MRI among Chinese at the age of 55-65 years: the Taizhou Imaging Study. *Sci Rep.* 2019;9:464.
42. Wang L, Lin H, Peng Y, et al. Incidental brain magnetic resonance imaging findings and the cognitive and motor performance in the elderly: the Shanghai Changfeng study. *Front Neurosci.* 2021;15:631087.
43. Appelbaum PS, Parens E, Waldman CR, et al. Models of consent to return of incidental findings in genomic research. *Hastings Cent Rep.* 2014;44:22-32.
44. Back AL, Arnold RM, Baile WF, Tulskey JA, Fryer-Edwards K. Approaching difficult communication tasks in oncology. *CA Cancer J Clin.* 2005;55:164-177.
45. Cole C, Petree LE, Phillips JP, Shoemaker JM, Holdsworth M, Helitzer DL. 'Ethical responsibility' or 'a whole can of worms': differences in opinion on incidental finding review and disclosure in neuroimaging research from focus group discussions with participants, parents, IRB members, investigators, physicians and community members. *J Med Ethics.* 2015;41:841-847.
46. Rancher CE, Shoemaker JM, Petree LE, Holdsworth M, Phillips JP, Helitzer DL. Disclosing neuroimaging incidental findings: a qualitative thematic analysis of health literacy challenges. *BMC Med Ethics.* 2016;17:58.
47. Bhaskar SMM. An equity and justice-informed ethical framework to guide incidental findings in brain imaging research. *Clin Pract.* 2023;13:116-124.
48. Shoemaker JM, Cole C, Petree LE, et al. Evolution of universal review and disclosure of MRI reports to research participants. *Brain Behav.* 2016;6:e00428.

### SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

**How to cite this article:** Kota K, Dawson A, Papas J, et al. Factors associated with attitudes toward research MRI in older Asian Americans. *Alzheimer's Dement.* 2024;10:e12449. <https://doi.org/10.1002/trc2.12449>