

# Recruitment: what we don't know and what we need to know

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# Recruitment and retention

- The decision to enroll in research involves the perception, assessment and judgment of risks and benefits
  - physical, hassles of time and travel, placebo (uncertainty)
  - benefit to patient, help others
- Much of the thinking on recruitment and retention views it as an exchange of information
  - Informed consent – disclose the risks/benefits, you say them back to me and then you make a decision
  - But that's not how AD dyads seem to make the decision.... How can this inform strategies for recruitment and retention?

# Recruitment and retention

- Studies both at enrollment and after participation suggest three reasons why people say they enroll
  - Trust
    - In investigator, university/institution, sponsor
  - Altruism
    - To family, people like them, society
  - Expectation of personal benefit
    - Health
    - Money
    - Attention
    - Someone to talk to

# Recruitment and retention

Trust as a reason to enroll:

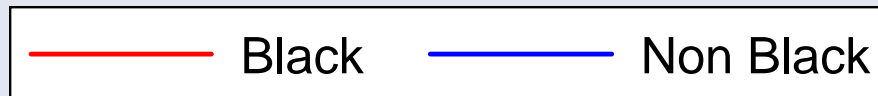
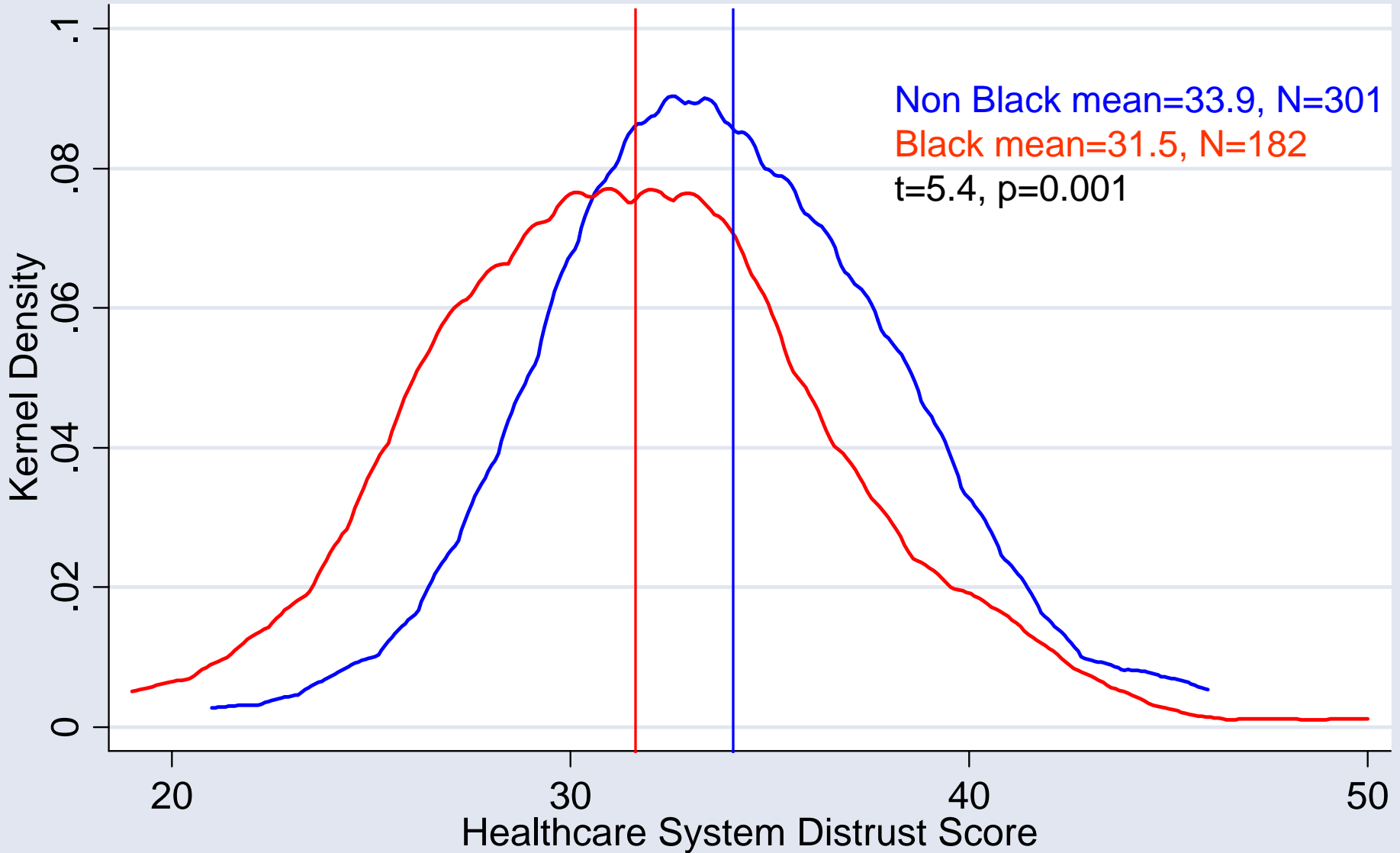
“Essentially, I'm going based on if Doctor Clark is in it, and the clinic is in it, and other people at the university and other patients at the university are in it, then it looks like a pretty good bet.”

# Recruitment and retention

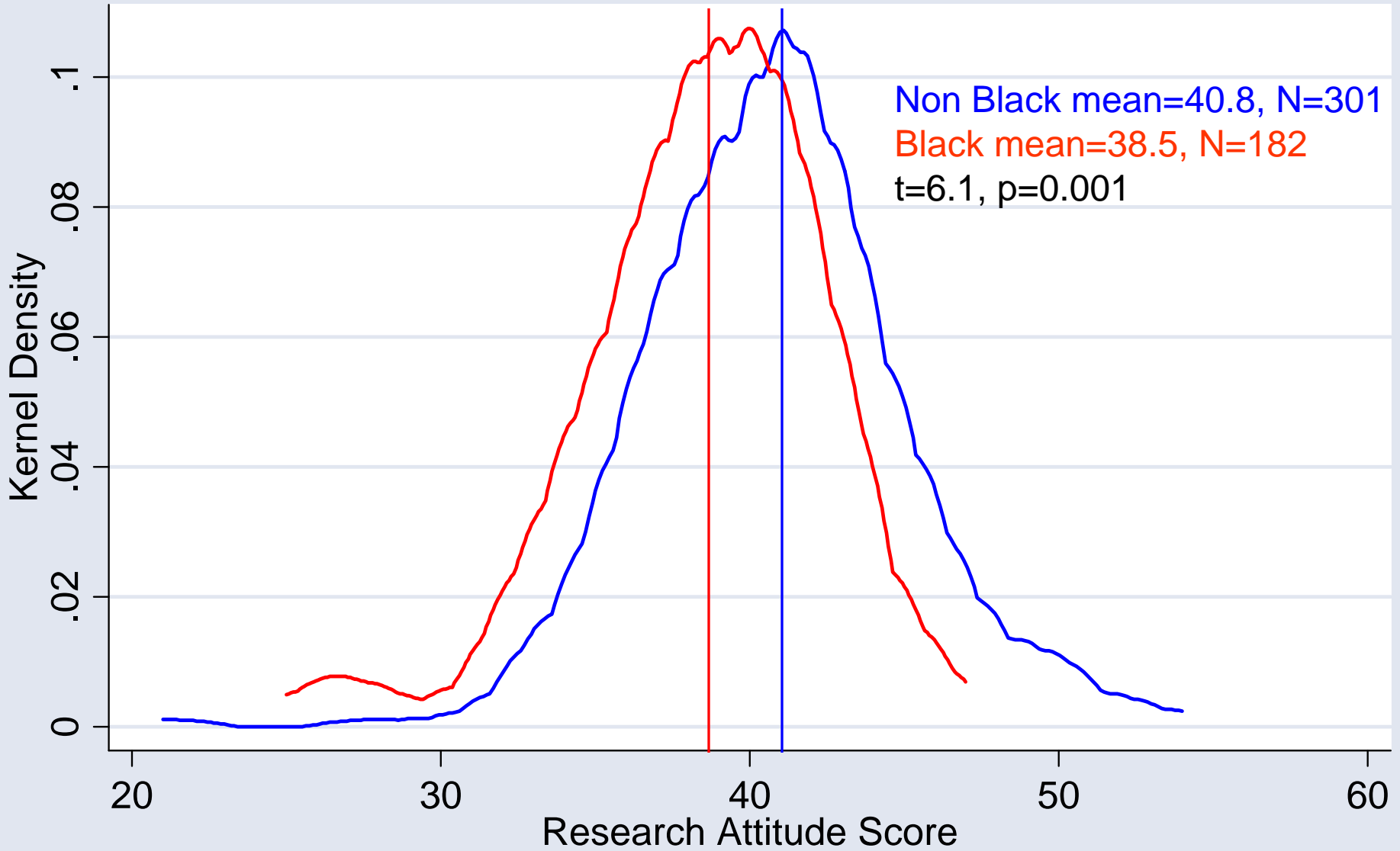
Altruism and benefit as reasons to enroll:

A) My wife is very altruistic and she is to one end of the scale about helping others. She believes in helping others all the time in any situation. B) She felt very strongly about the fact that her mother had had Alzheimer's and wished that somebody had participated in some kind of study before her mom had Alzheimer's so that something could have been done. And C) of course, she felt there's a possibility that she may benefit from it."

# Health Care System Distrust: Black and Non Black

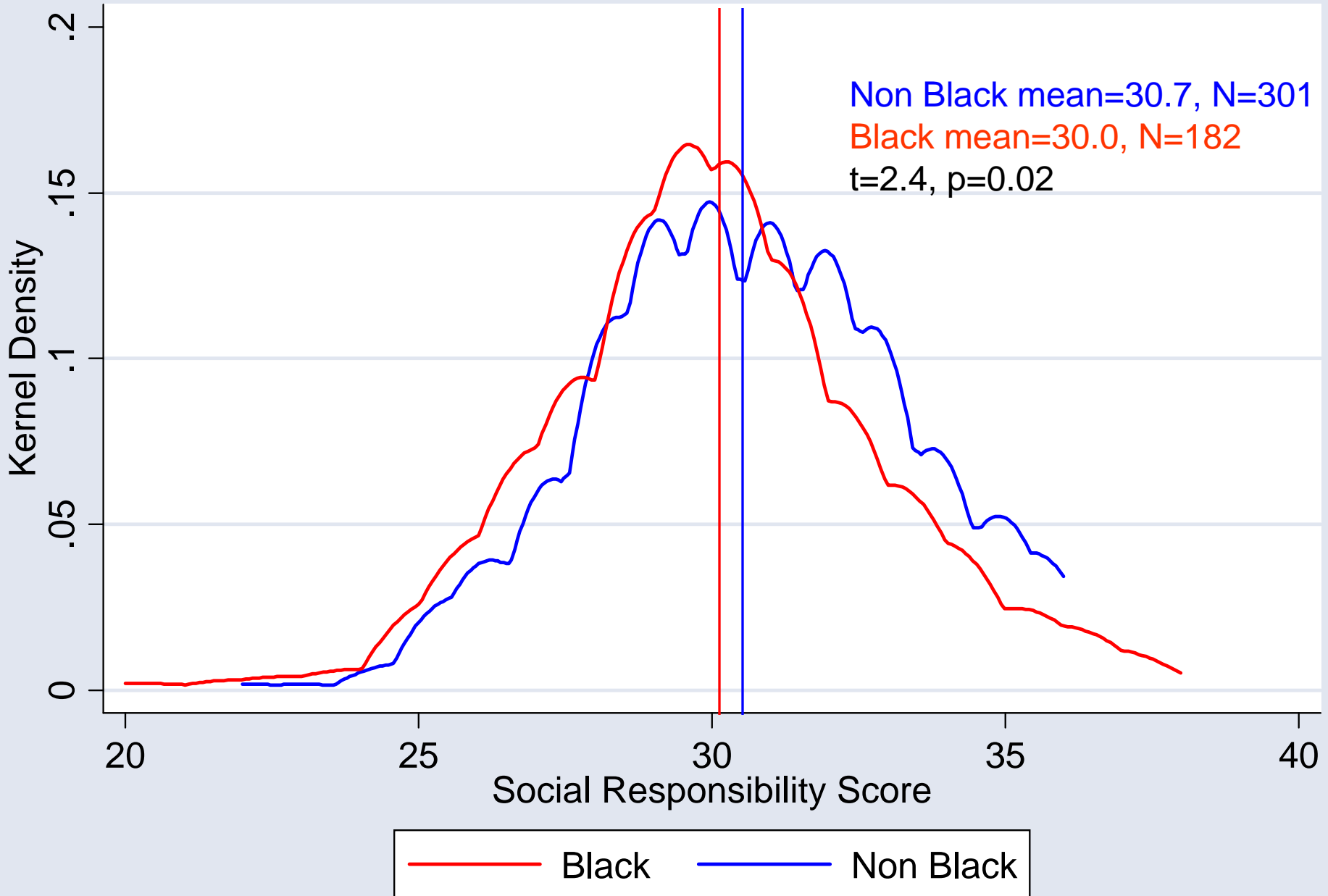


# Research Attitude: Black and Non Black



— Black — Non Black

# Social Responsibility: Black and Non Black





# Recruitment and retention

- Phone survey of 438 persons age > 49 (~50% age 50 - 60)
- “A clinical trial is a medical research study in which scientists observe the course of a disease in human beings or evaluate the effectiveness of a therapy or treatment. Usually participants will receive some free medical care and may also receive the latest treatment.

“If asked, would you consider participating in a clinical trial designed to test a medical treatment if you had a serious medical illness such as cancer?”

# Recruitment and retention

If asked, would you consider participating in a clinical trial designed to test a medical treatment if you had a serious medical illness such as cancer?

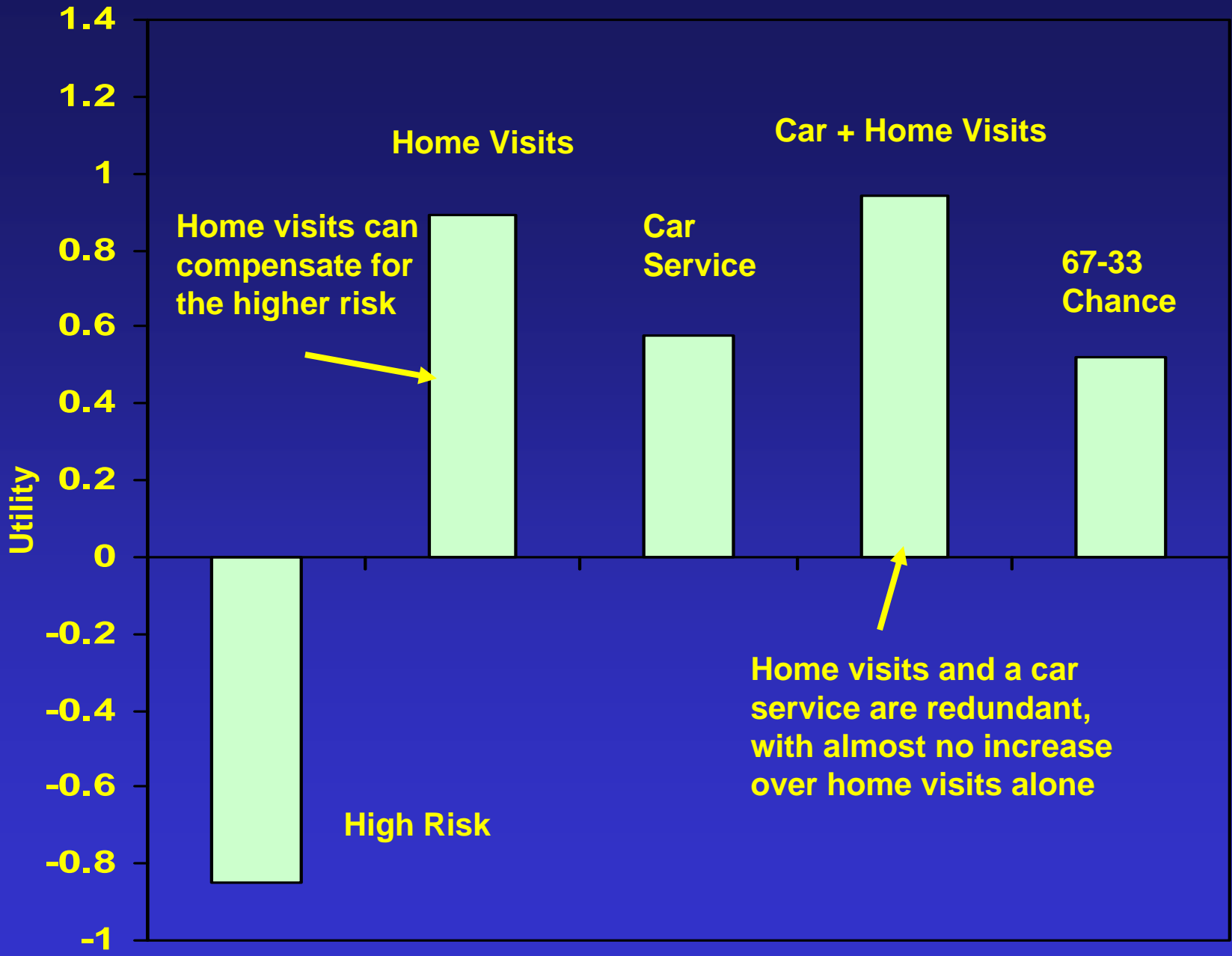
	Yes	No
White	78.2%	21.8%
Black	72.5%	27.8%
	$X^2=3.299, p<0.07$	

# Recruitment and retention

- One retrospective study surveyed carers of patients enrolled (n=29) and those not enrolled (2nd<sup>ary</sup> to eligibility criteria) (n=15) in an RCT
- Postal questionnaire sent from study site, potentially anonymous, signed by clinician unknown to the recipient
- Of those randomized...
  - 60% felt their relative was no better
  - 59% were concerned relative was on placebo
  - 75% felt expectations as a whole were mod/extr well met
- Most (67% & 77%) would *do it again* and *recommend it to others* (97% & 100%)

# Recruitment and retention

- The decision to enroll in research, and to stay in, is a multi-attribute decision
  - Just like other decisions: buying a car or a house, selecting a vacation spots, etc.
  - Multi-attribute decisions involve trade-offs
- People can list out many features or attributes they think are important,
  - but, experimentally, we generally find just 3 or so features drive choice



By offering home visits and a 67-33 chance, we double the predicted willingness to participate over baseline

Scenario	Predicted willingness to participate N(%)
Low risk, home visits, 67-33 chance	65 (60%)
Low risk, home visits	51 (47%)
<u>High risk, home visits, 67-33 chance</u>	<u>45 (42%)</u>
High risk, home visits	29 (27%)
High risk, 67-33 chance	27 (25%)
Low risk and no amenities	26 (24%)
High risk, car service	20 (19%)
<u>High risk and no amenities (the usual AD RCT)</u>	<u>18 (17%)</u>

# Recruitment and retention

- A closer look at the reasons....
- Expectation of benefit
  - Learning about AD
  - Getting AD better, maybe...
- Altruism
- Expectation of benefit
  - Someone to talk to
  - Relationships
  - Feeling good

# Recruitment and retention

- A closer look at the reasons....

## Information/knowledge related goals

- Expectation of benefit
  - Learning about AD
  - Getting AD better, maybe...

## Emotional goals

- Altruism
- Expectation of benefit
  - Someone to talk to
  - Relationships
  - Feeling good



# Recruitment and retention

## Socioemotional selectivity theory

As people approach the end of life, there is an increasing saliency of emotional goals.

If a person perceives future time as limited...

- emotionally meaningful goals, *to the extent they have immediate payoffs*, have saliency over knowledge-related goals that aim to increase the chance of future payoffs

# Recruitment and retention

- Emotional well being improves with age
- Emotion gains centrality in everyday life as people age
- Older adults are motivated to
  - avoid negative emotions
  - seek positive emotions
  - remember events with a positive emotional valence

# Recruitment and retention

Emotionally meaningful ad  
copy

Watch ad

“Take time for the ones you love”

Airline ad

“Take flight.... Your loved ones await”

Knowledge-related ad  
copy

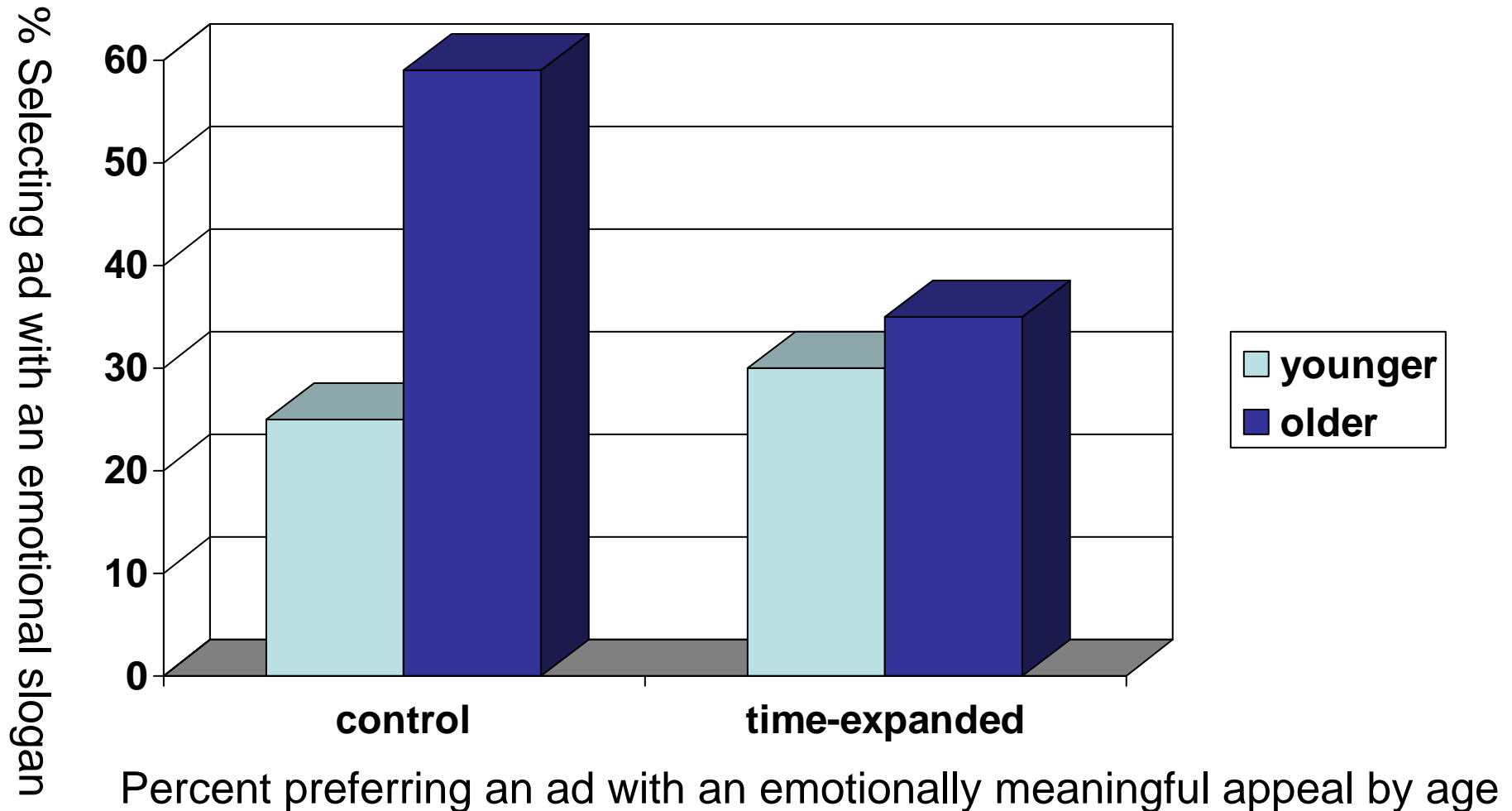
Watch ad

“Take time for success”

Airline Ad

“Take flight.... Expand your horizons.”

# Recruitment and retention



# Recruitment and retention

- If you feel your time is limited, you want to maximize emotional goals over goals of getting information and knowledge
  - especially if getting knowledge and info is painful or otherwise emotionally annoying
- Much of the thinking on recruitment and retention views it as an exchange of information
  - Informed consent – disclose the facts
- But what if participation in research was a way to reduce emotional strain (i.e., maximize emotional goals)....
  - Who enrolls in research and why?

# Recruitment and retention

- Who are the kinds of CG-PT dyads who enroll in RCTs? Results of an informal poll & lit search...
  - ADCS Site A: 70% spousal CG
  - ADCS Site B: 100% spousal CG
  - ADCS Site C: 80% spousal CG
  - ADCS Site D: 70% spousal CG
  - 13 sites in ADCS CLASP trial: 75% spousal CG
  - Australian site for RCT: 75%

# Recruitment and retention

- Typical caregiver is a woman in her mid-40's, who works full time, high school grad, and annual household income of \$35K
- In 1991, CSHA-1 nationally representative samples of Canadians aged 65 or older living in the community ( $n = 9,008$ ) and in institutions
  - $N = 1,472$  informal caregivers
  - Seventy percent of caregivers were women, 80% daughters, sons, or other relatives; spouses 27% of those w/o dementia and 18% w/ dementia
  - The mean age 64 years
- PENN ADC: 51% adult children, 44% spouse

# Recruitment and retention

Differences between spousal vs non-spousal caregiver willingness to enroll in an AD clinical trial

AD clinical trial features	Spouses (n=56)	Non-spouses (n=47)
All PENN, high risk (usual trial)	21.4%	8.5%
All PENN, low risk	35.7%	8.5%
Home visits, low risk study drug	62.5%	31.9%
Home visits, high risk study drug	32.4%	21.3%



# Recruitment and retention

- CGs of patients who enrolled described an automatic or pre-deliberative decision
  - willing to enroll before receiving any info from contacts or informed consent session
  - “I was pretty much well ready to enroll him when the study was first mentioned [A898, line 59-61].”
- Several attributed predisposition to enroll to desperation to find help for relative

# Recruitment and retention

“You just get involved in something and you go for it. You don’t separate one thing from the other in minute detail and say well I like this but I don’t like that, or this is an invasion of privacy but this isn’t. We don’t care. What we’re just looking for is the answer to our prayers, that’s all [C064, lines 741-748].”

# Recruitment and retention

“It wasn’t a long dissertation. I’ll try anything that might work. This might be the thing that would do it. I don’t know anybody who’s in this study and I don’t know what [name of pharmaceutical company] calculations are or who approved this. I have no idea but we’re willing to try [A919, II 599-603].” This same caregiver went on to explain “Things are not doing so well. We’ll try something that might [work]. To me, it was a quick decision. I didn’t ponder over this or anything, I’ll just do anything that might work. And, this was one of the options, the only option really [A919, II. 612-16].”

**Comparison of AD patient and caregiver performance on measures of decision making ability**

AD Patients (n=59)    Caregivers (n=60)				
<b>Ability to understand</b>	N	%	N	%
25-26	9	15%	51	85%
23-24	6	10%	7	12%
21-22	10	17%	2	3%
19-20	5	8%	0	0%
17-18	4	7%	0	0%
15-16	6	10%	0	0%
13-14	6	10%	0	0%
1-12	13	22%	0	0%
0	0	0%	0	0%
Mean (SD)	17.3 (6.6)		25.4 (1.1)	

# Recruitment and retention

- CGs of patients who did not enroll described a more deliberative process
  - discussions with drug study coordinator and family
  - reviewing consent form
  - weighing the reasons
  - “mulling the information over”
  - “making an informed decision”

# Recruitment and retention

- One retrospective study surveyed carers of patients enrolled and those not enrolled in an RCT
- Of those randomized...
  - 60% felt their relative was no better
  - 59% were concerned relative was on placebo
  - 75% felt expectations as a whole were moderately to extremely well met
- Most (67% & 77%) would do it again and recommend it to others (97% & 100%)

# Recruitment and retention

- Of those randomized...
  - 92% reported overall participation moderately to extremely well met their goals
  - 84% would miss staff contact
  - 64% felt emotionally better
    - 32% of PT felt emotionally better
  - 53% were sad they finished

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# Recruitment and retention

- What kinds of messaging will bring people into research?  
Will keep people in research?
  - Messaging – slogans, brochures, telephone scripts, appearance of the center
  - H: Messaging that fosters trust in the system.
  - H: Messaging that focuses on how research fulfills emotional goals: altruism, relieving desperation, feeling good
- How does the effects of messaging differ by relevant groups: adult children CG, race, class?
- Why are adult children CG/younger CG – AD patient dyads less likely to participate in AD clinical trials?
  - H: Amenities that reduce hassles of participation (home visits) will improve recruitment and retention.

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