

Health Disparities as a Focal Point in Clinical and Translational Research: Lessons from Chronic Kidney Disease

Neil R. Powe, MD, MPH, MBA
Professor of Medicine and Epidemiology
Director, Welch Center for Prevention,
Epidemiology and Clinical Research
The Johns Hopkins Medical Institutions

npowe@jhmi.edu

Overview

- A premise
- Nature of race and ethnic disparities
- Mechanisms, barriers and progress
 - Kidney disease examples of health and health care disparities
 - General and other illustrative examples of health and health care disparities
- The opportunity that lies right before our eyes

Premise

Science on disparities ...
clinical care with diverse patients...
and
education about disparities...
...enhances all of Medicine
and human health.

Disparities: What do we mean?

- Disparity (dis per'ə tē) *n.* a difference or lack of **equality**/ --pl. –ties
- Health Care should be:
 - Safe
 - Effective
 - Patient centered
 - Timely
 - Efficient
 - **Equitable** = providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location or socio-economic status

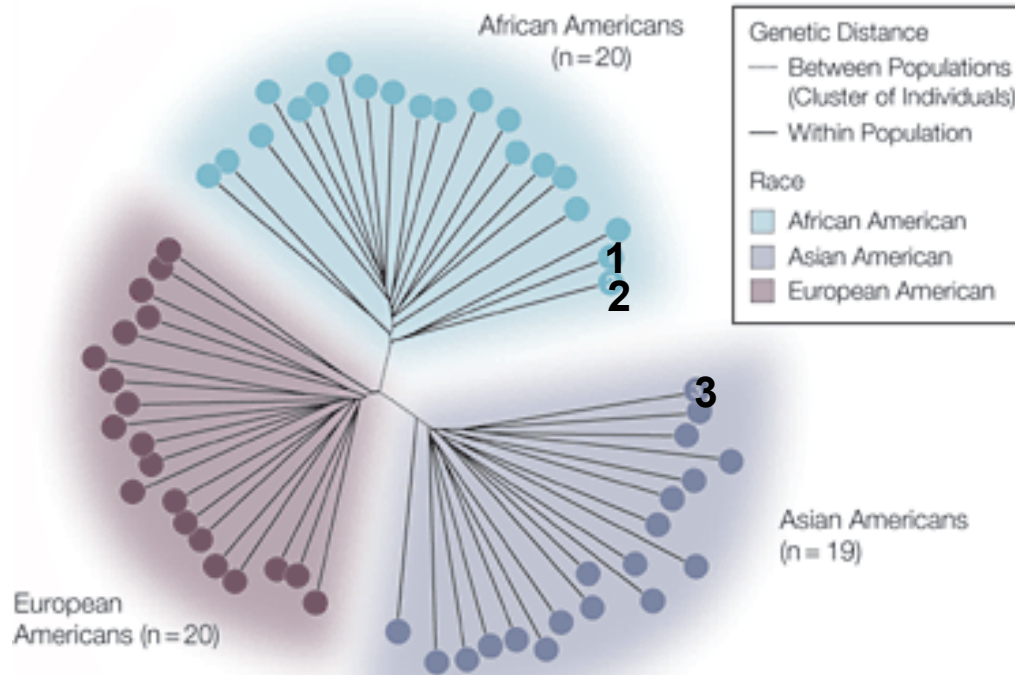
Institute of Medicine

Race: What do we mean?

- Race (rās) *n.* a group of people united or classified together on the basis of common history, nationality, or geographic distribution
Webster's New World Dictionary, Revised Edition, 1996
- “a construct of human variability based on perceived differences in biology, physical appearance and behavior”,-- not a biological reality. *Institute of Medicine, United States*
- “Information about genetic group membership captured by notions of race is, in general, less than that obtained by making inferences of ancestry from geographic or explicit genetic data” *Bamshad M.*

Inference of Individual Ancestry Proportions From Genetic Data

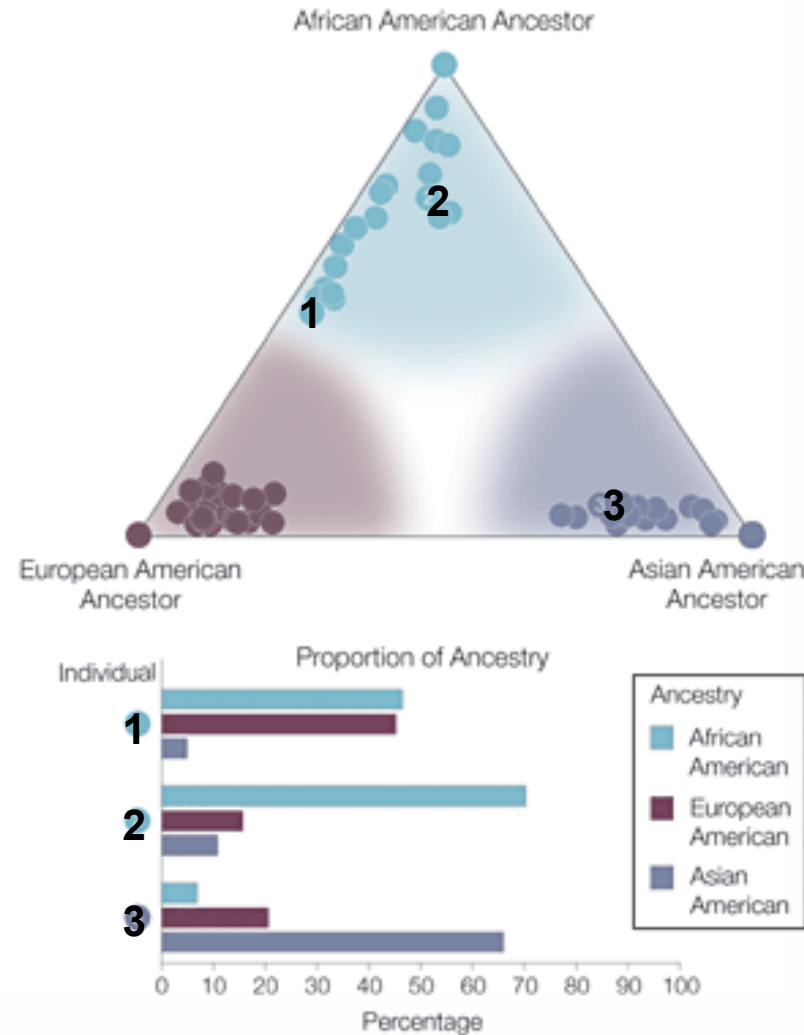
A Network of Genetic Relatedness



B Examples of Genetic Distance

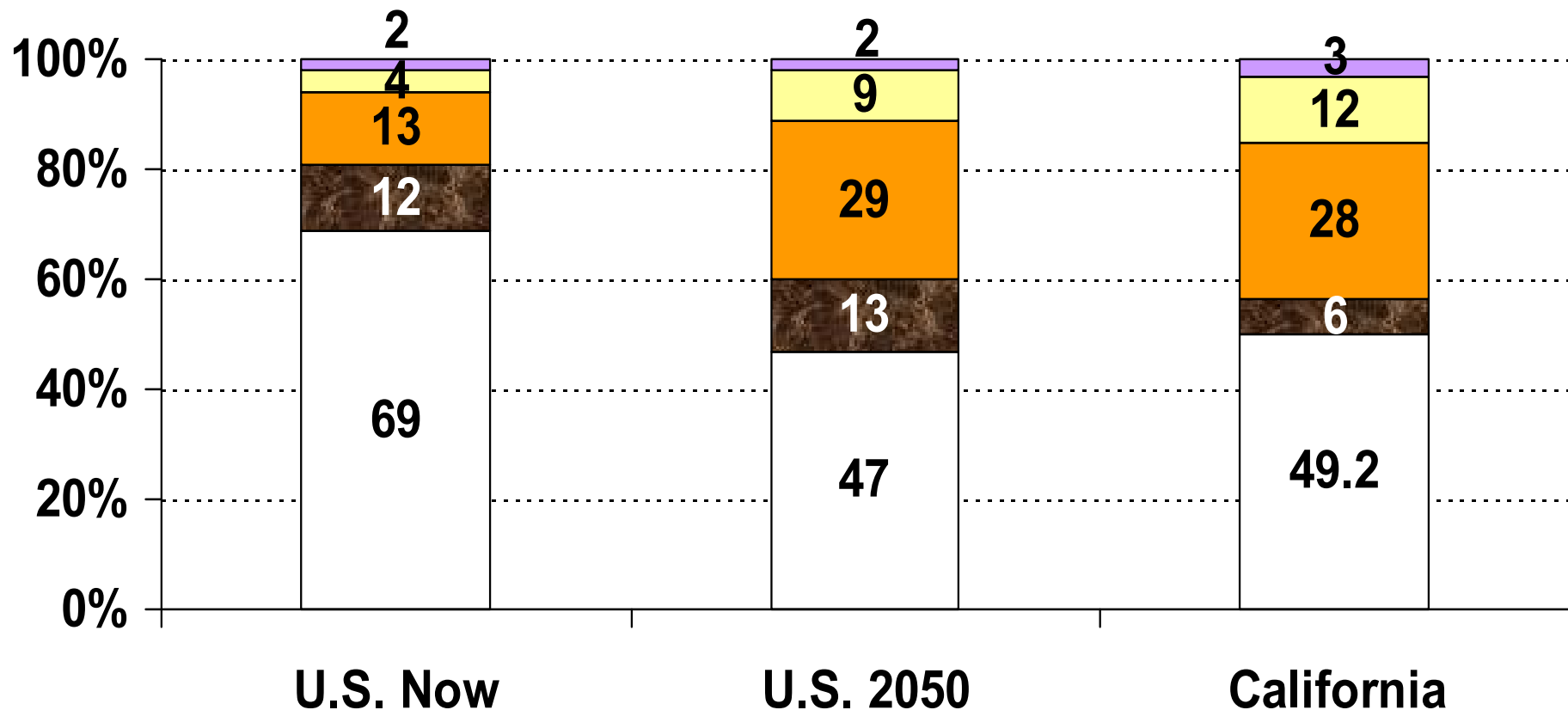


C Inferred Ancestry



Bamshad, M. JAMA 2005;294:937-946.

Race/Ethnic Composition, United States



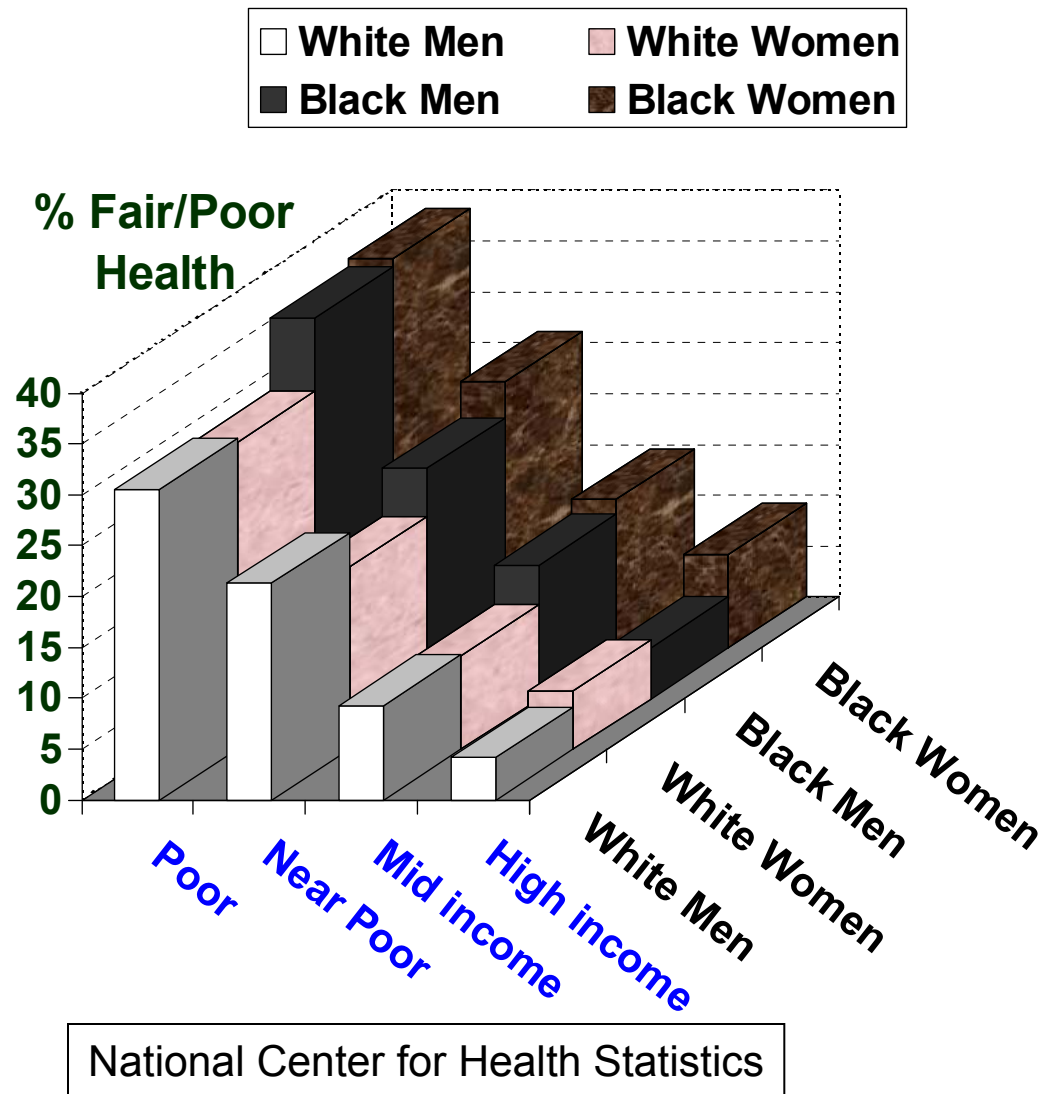
Non-uniformity of *health* among racial and ethnic groups is extensively documented

- *Life expectancy at birth* – Blacks vs. Whites, 10 year gap for men, 5 year gap for women
- *Infant mortality rate* – Blacks and Native Americans twice as high vs. Whites.
- *Death rate* – Blacks vs. whites: greater for cancer, diabetes, heart disease, HIV/AIDS, homicide; Hispanics vs. Whites: greater for diabetes
- *Morbidity* – For most ethnic minorities (Blacks, Native Americans, Hispanics and Asians) vs. Whites: higher for kidney failure; also for cancer, diabetes, hypertension, obesity, HIV/AIDS, tuberculosis, hepatitis
- Disparities persist even after accounting for socioeconomic status, insurance, lifestyle, and clinical factors

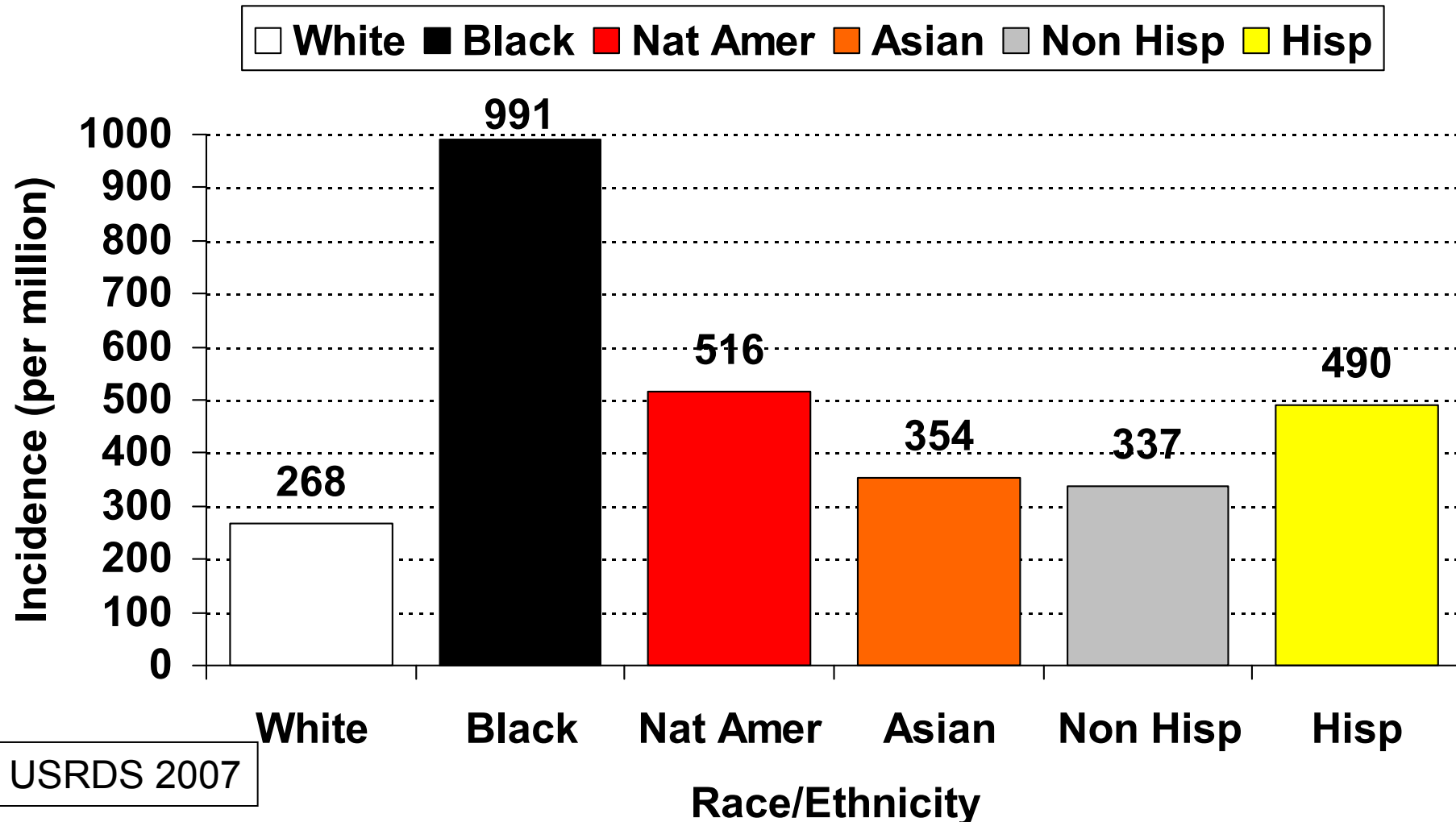
Race, Socioeconomic Status, and Health

To be a poor man is hard, but to be a poor race in a land of dollars is the very bottom of hardship

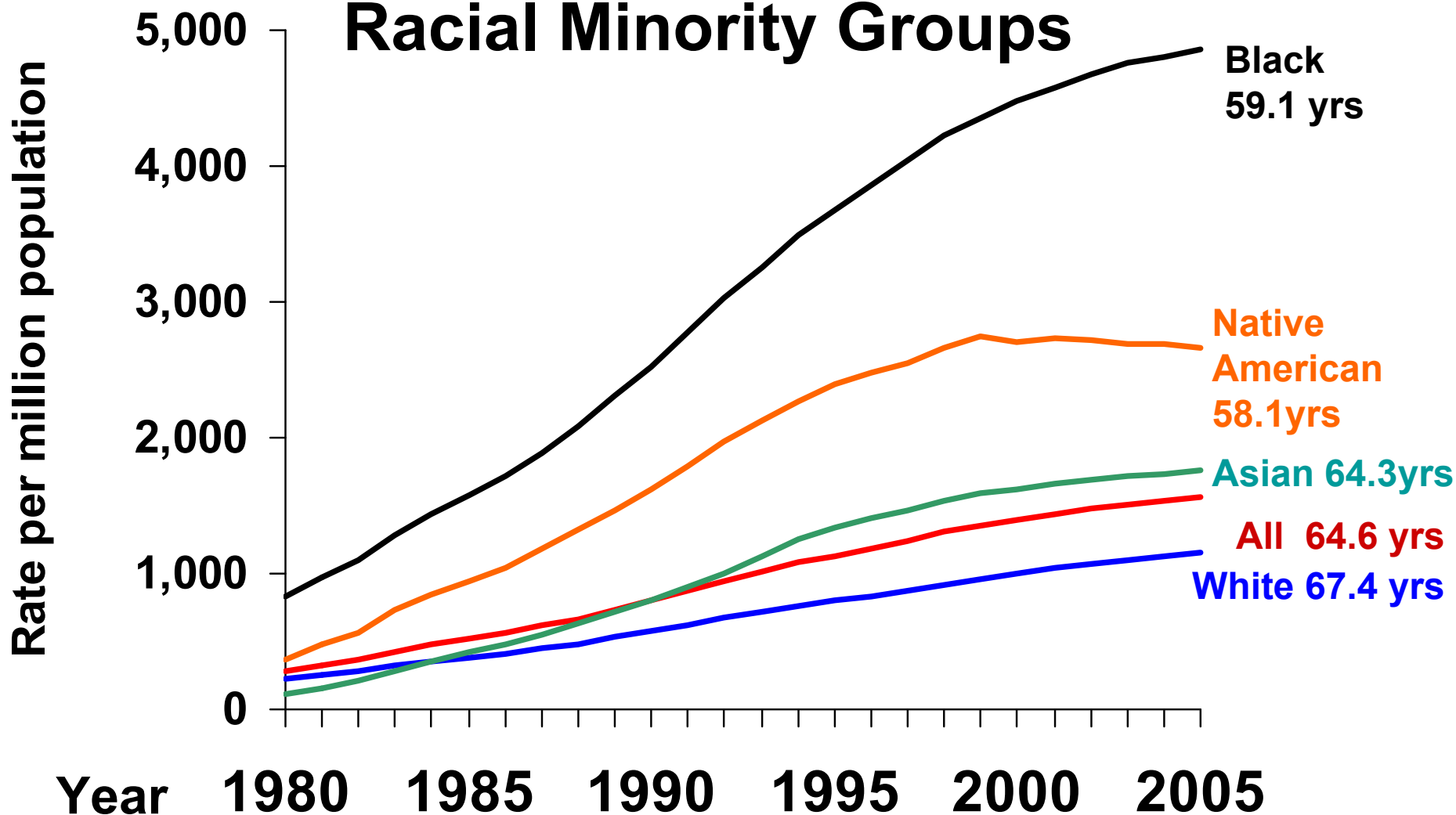
W. E. B. DuBois



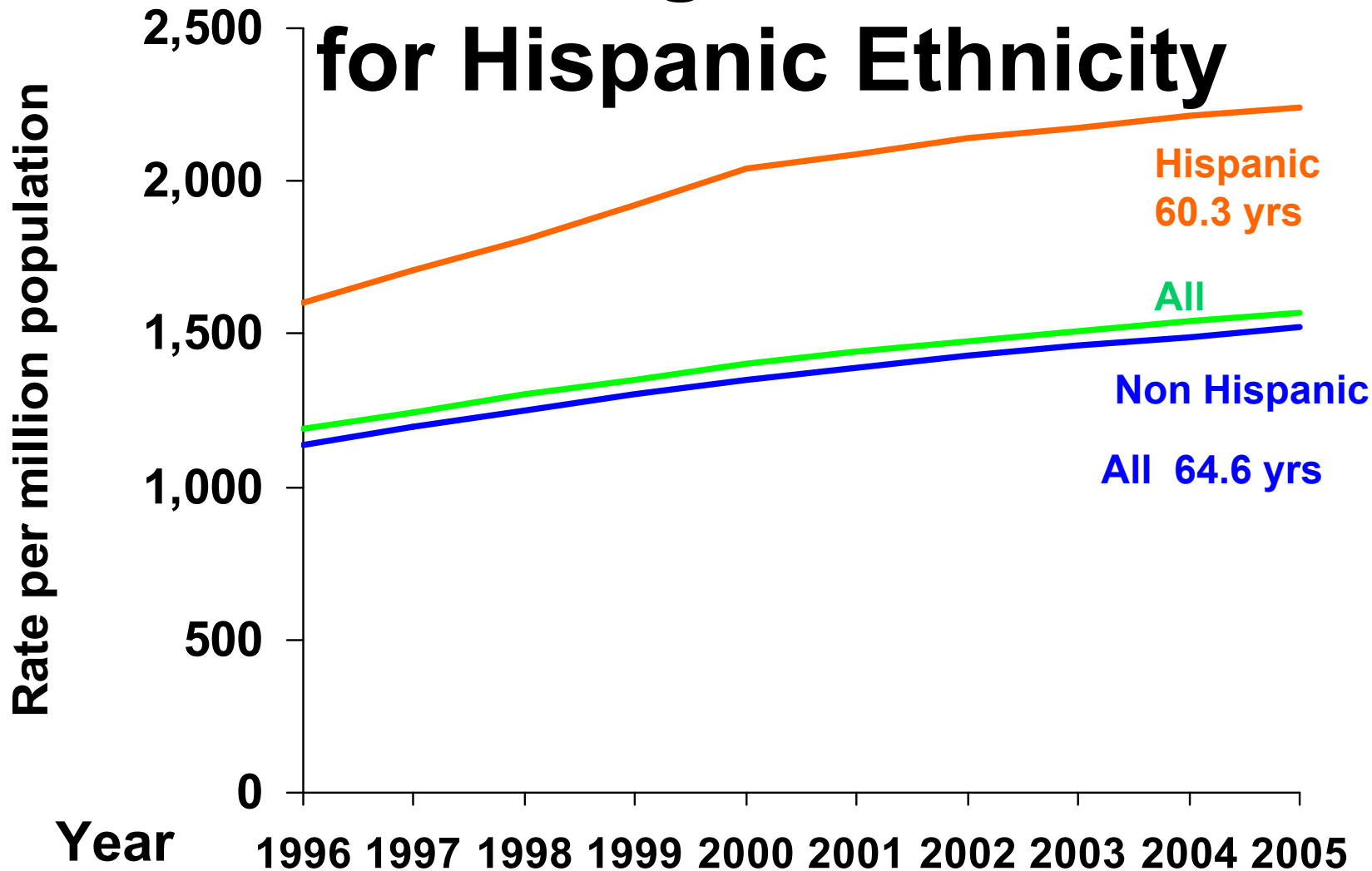
Incidence (per million) of kidney failure is up to 4 times greater in racial and ethnic minorities (2005)



ESRD Prevalence Rates are Greater and Average Age at Onset is Less for Racial Minority Groups



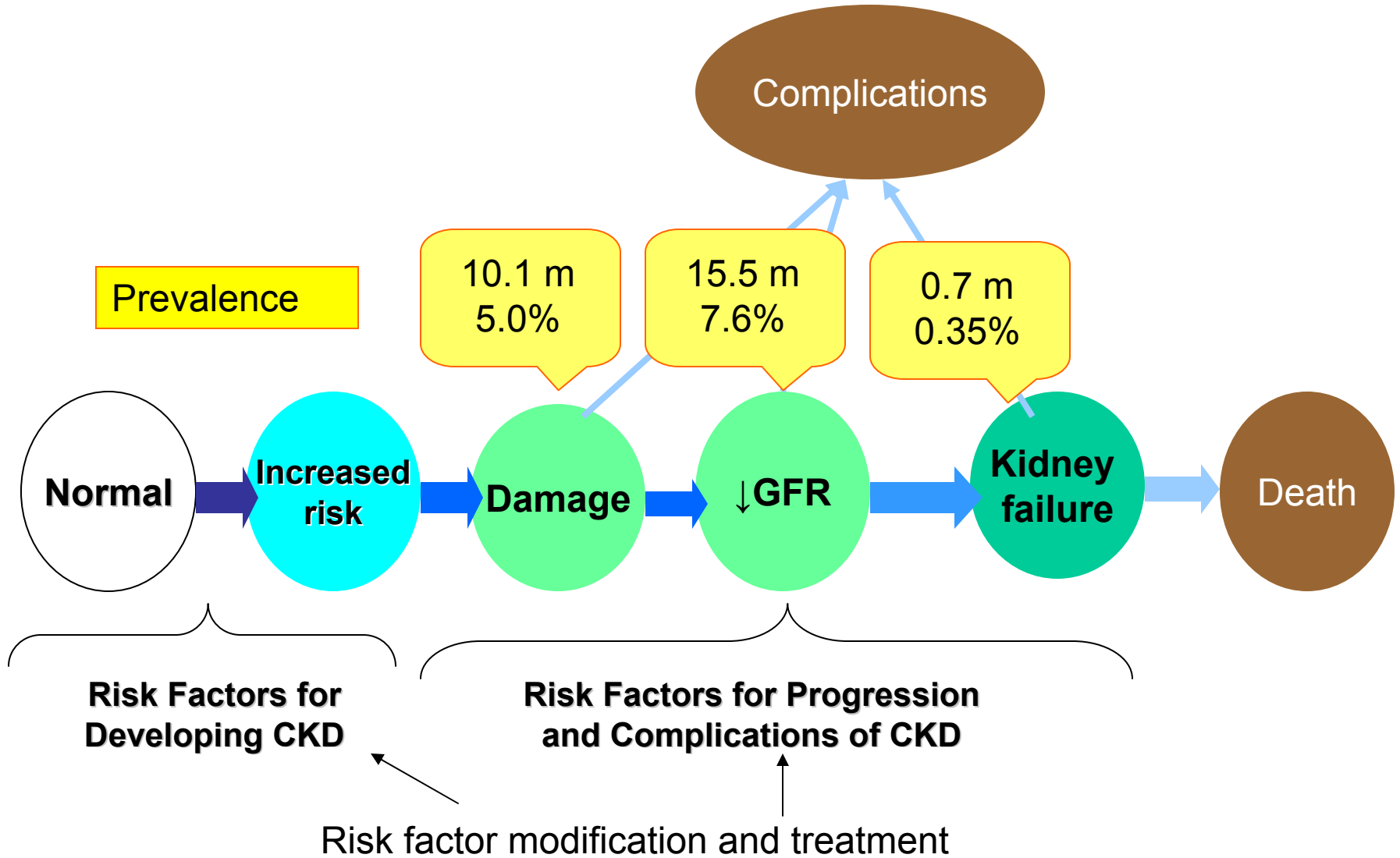
ESRD Prevalence Rates are Greater and Median Age of Onset is Less for Hispanic Ethnicity



USRDS Annual Data Report 2007

Rates adjusted for age and gender

Schema of CKD Progression



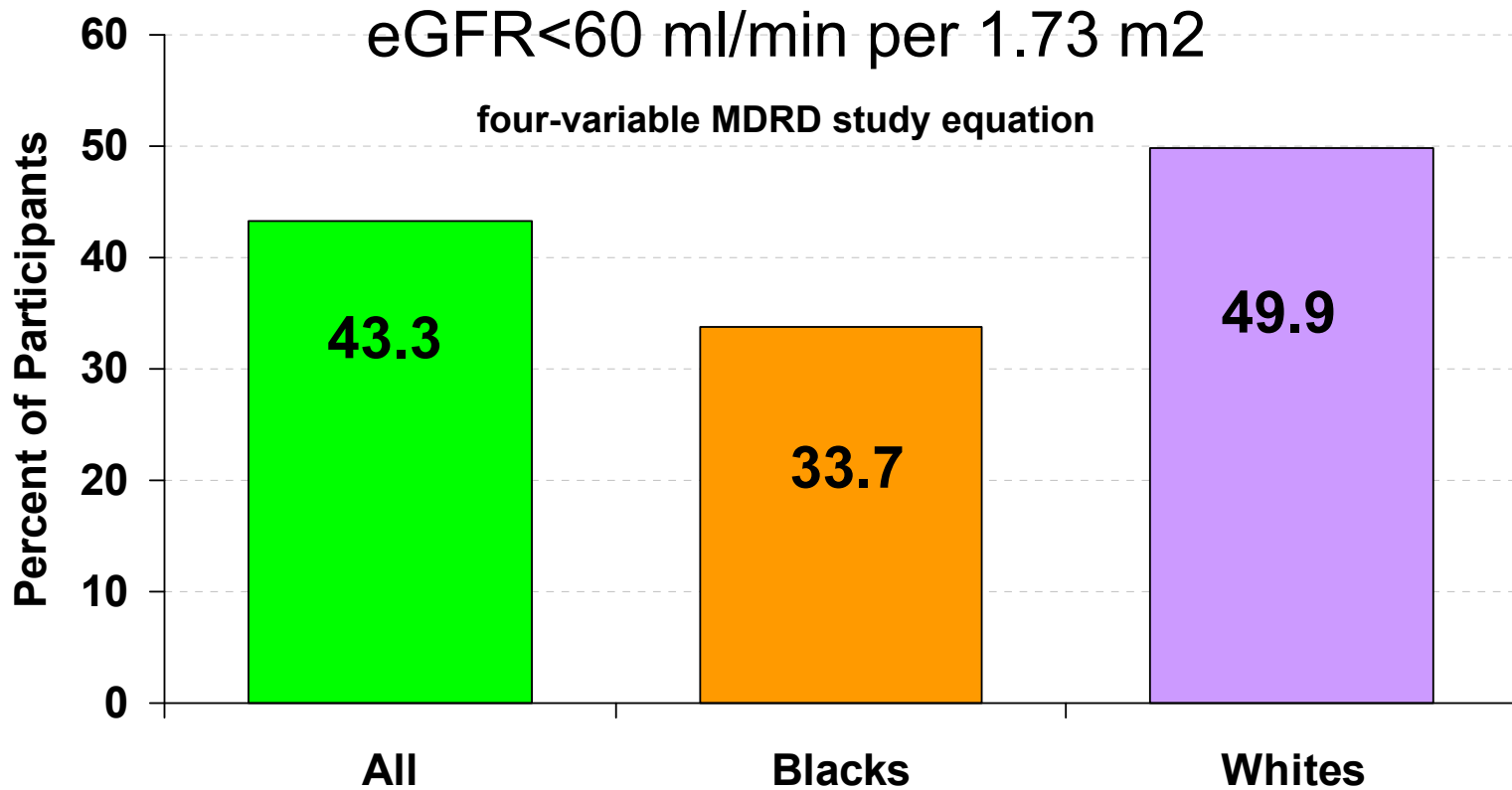
**Is there a greater prevalence of
earlier stages of CKD in
minorities?**

Prevalence of Chronic Kidney Disease in Renal

12,030 US residents 45 yr and older



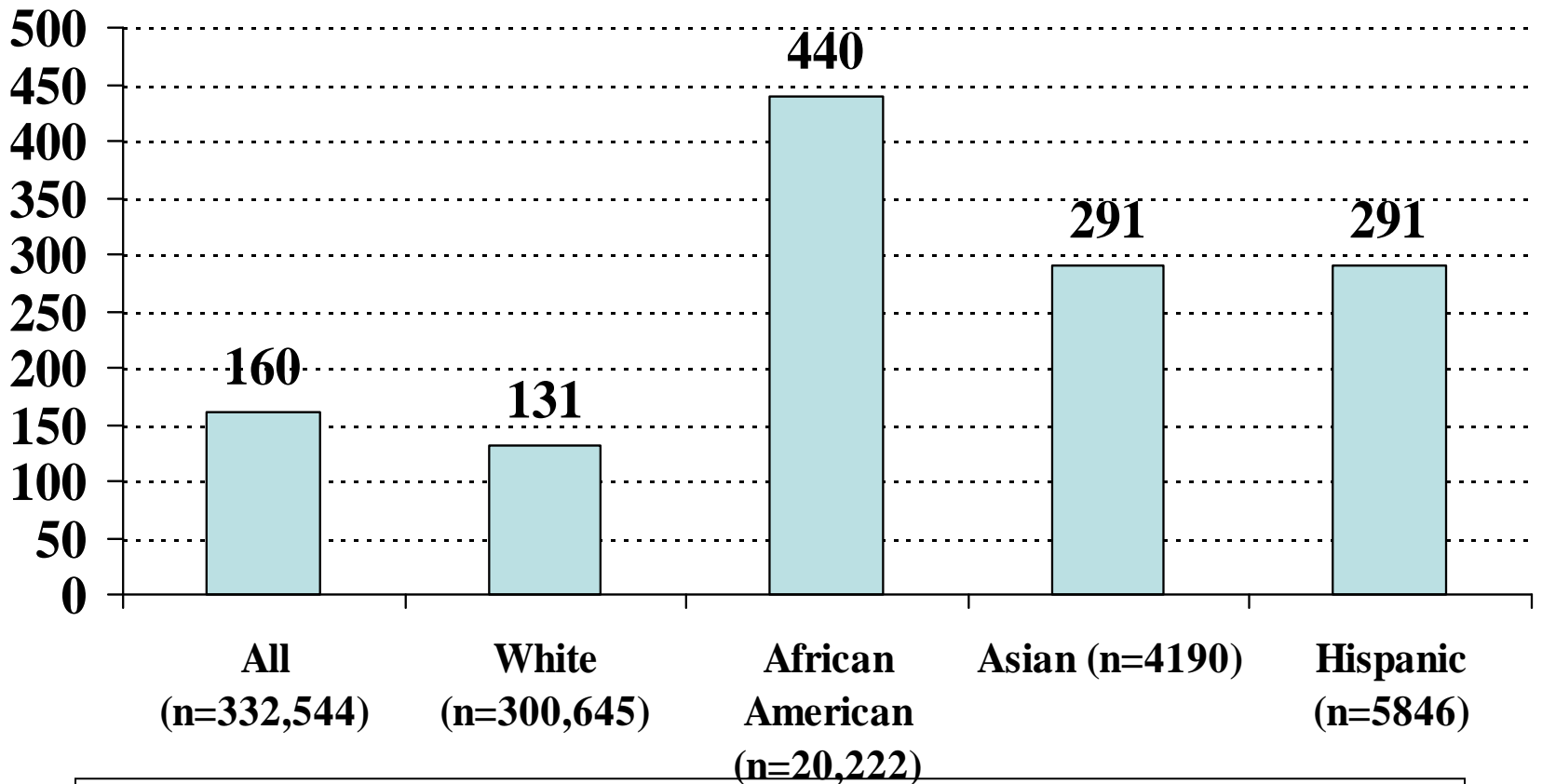
REGARDS
REasons for Geographic And Racial Differences in Stroke



McClellan W, Warnock DG, McClure L, Campbell RC, Newsome BB, Howard V, Cushman M, Howard G. Racial differences in the prevalence of chronic kidney disease among participants in the Reasons for Geographic and Racial Differences in Stroke (REGARDS) Cohort Study. *J Am Soc Nephrol.* 2006;17:1710-5.

Is there a greater rate of progression to ESRD in minorities independent of prevalence of earlier stages of CKD in minorities?

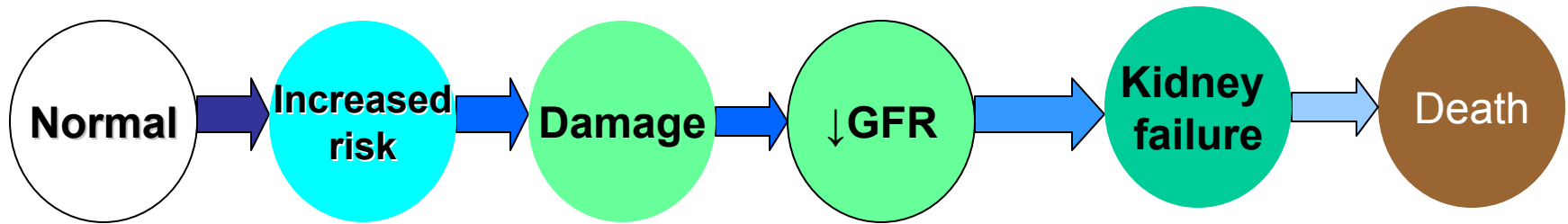
Ethnicity and Age-Adjusted Incidence per Million Person-Years of ESRD over 16 years in 300,645 white and 20,222 black men Screened for MRFIT



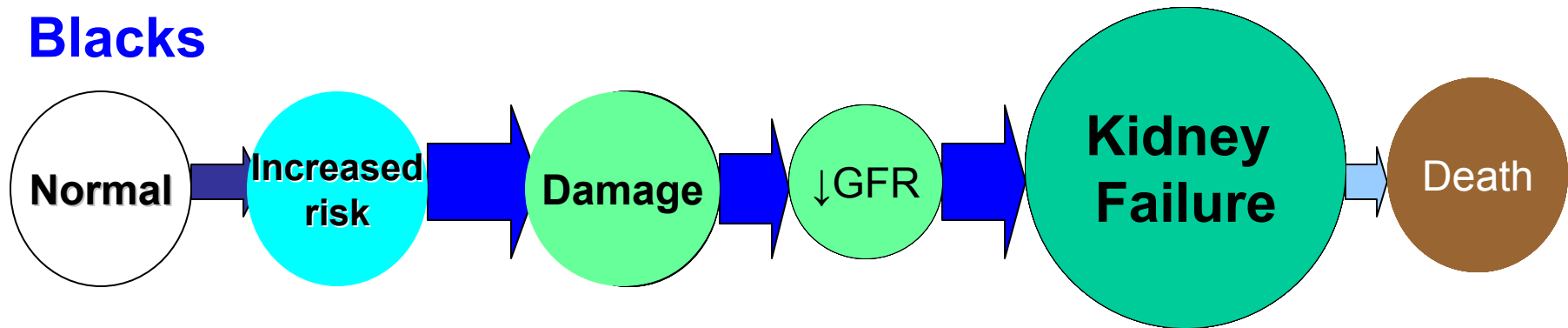
Klag MJ, Whelton PK, Randall BL, Neaton JD, Brancati FL, Stamler J. End-stage Renal Disease in African American and White Men. *JAMA* 1997; 277:1293-1298

The higher incidence of kidney failure among African Americans appears due to a faster rate of disease progression rather than greater prevalence of early stage CKD

Whites



Blacks

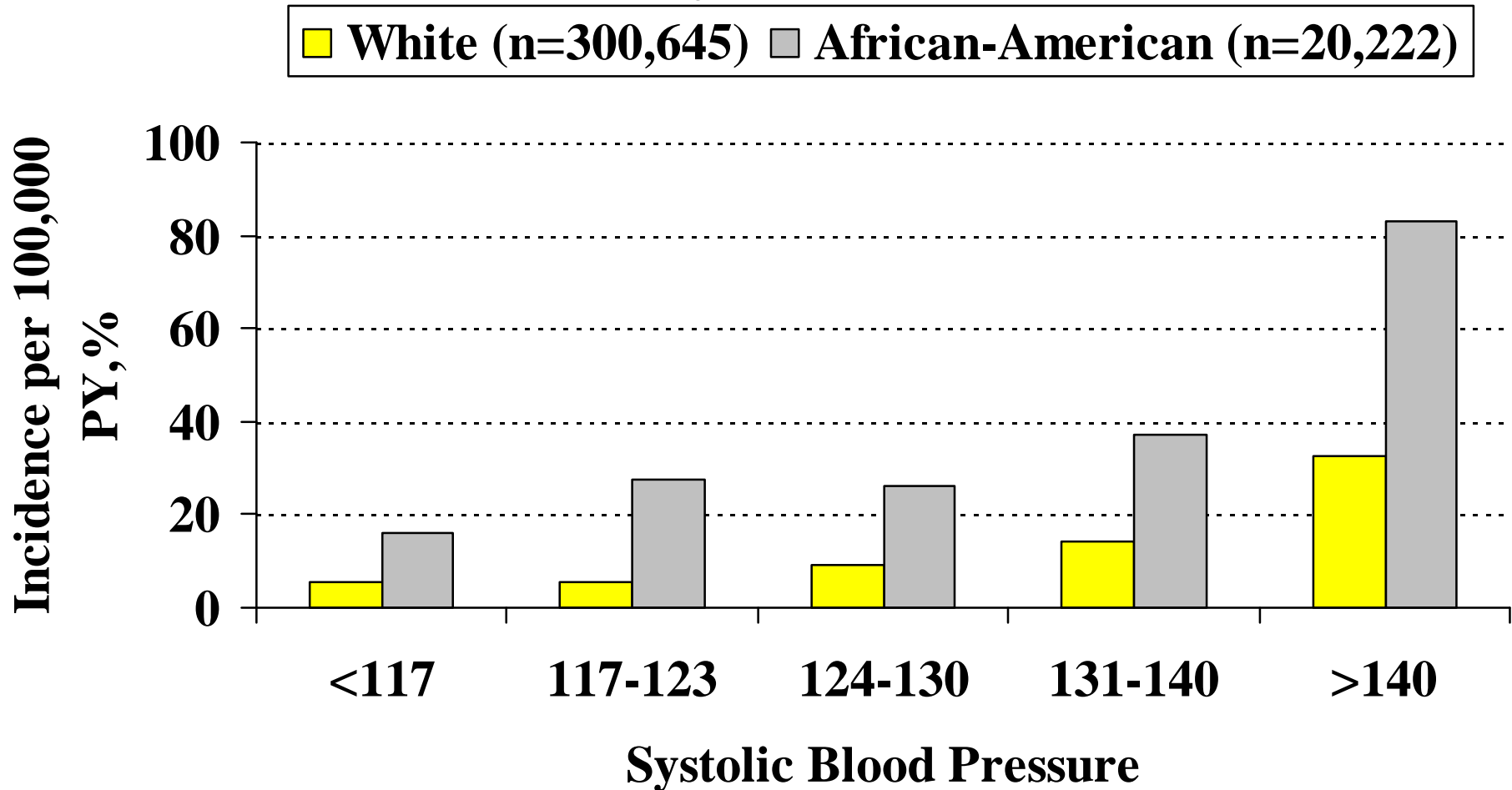


Potential Reasons for Disparities in Initiation and Progression of CKD

- demographic -- age
- biologic and clinical factors
 - [diabetes](#), [hypertension](#), obesity, dyslipidemia, autoimmune diseases, infections, stones, obstruction reduced kidney mass, hyperfiltration states, higher level of proteinuria, genetics
- socioeconomic status
- family history
- environmental factors
- psychosocial and cultural factors
- health risk behavior and lifestyles
- access to & quality of health care

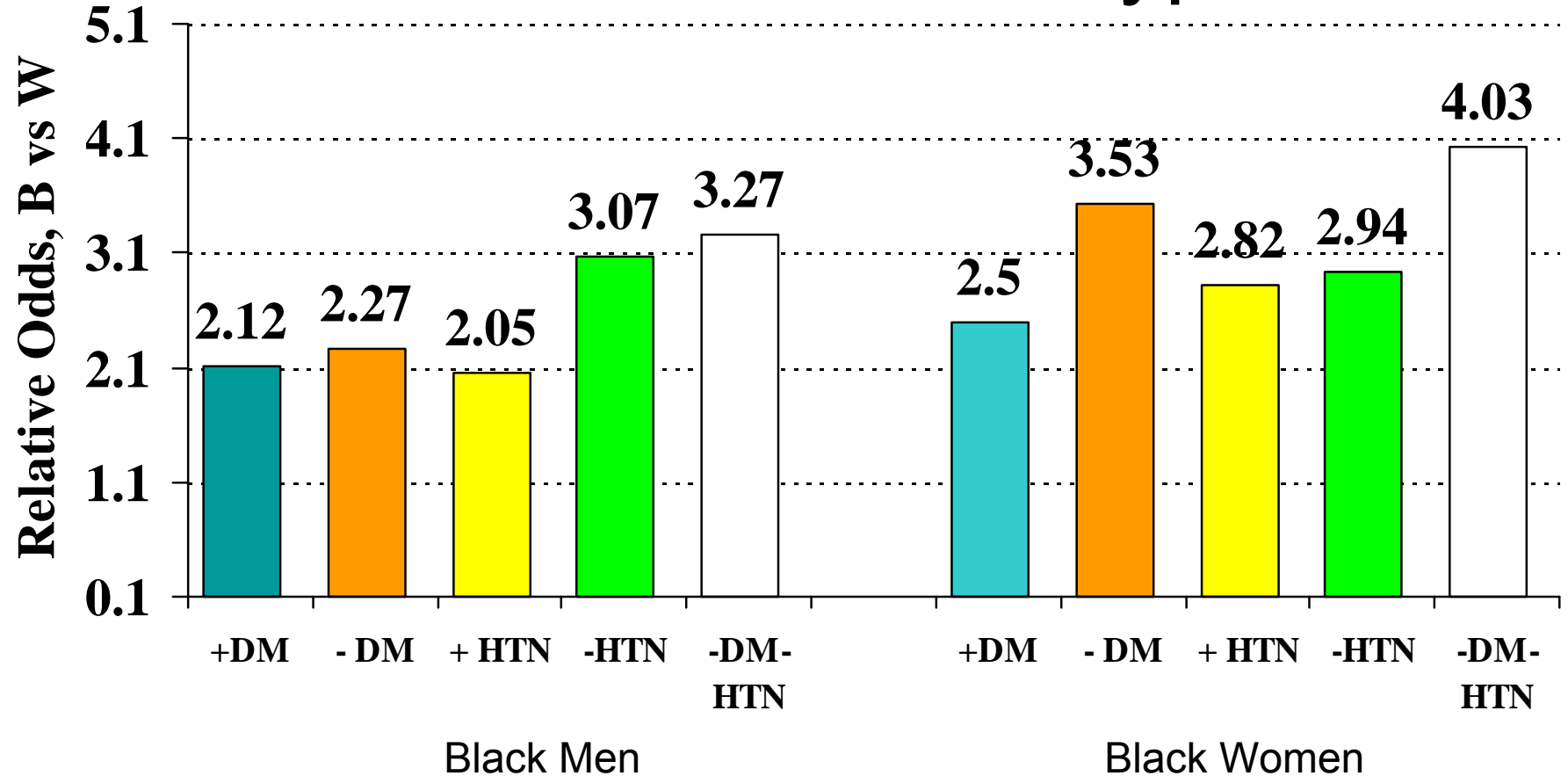
Can the greater rate of progression to ESRD in minorities be explained by more hypertension or diabetes?

Blacks have higher age-adjusted 16-year incidence of all-cause ESRD than Whites despite level of baseline systolic blood pressure



Klag MJ, Whelton PK, Randall BL, Neaton JD, Brancati FL, Stamler J. End-stage Renal Disease in African American and White Men. *JAMA* 1997; 277:1293-1298

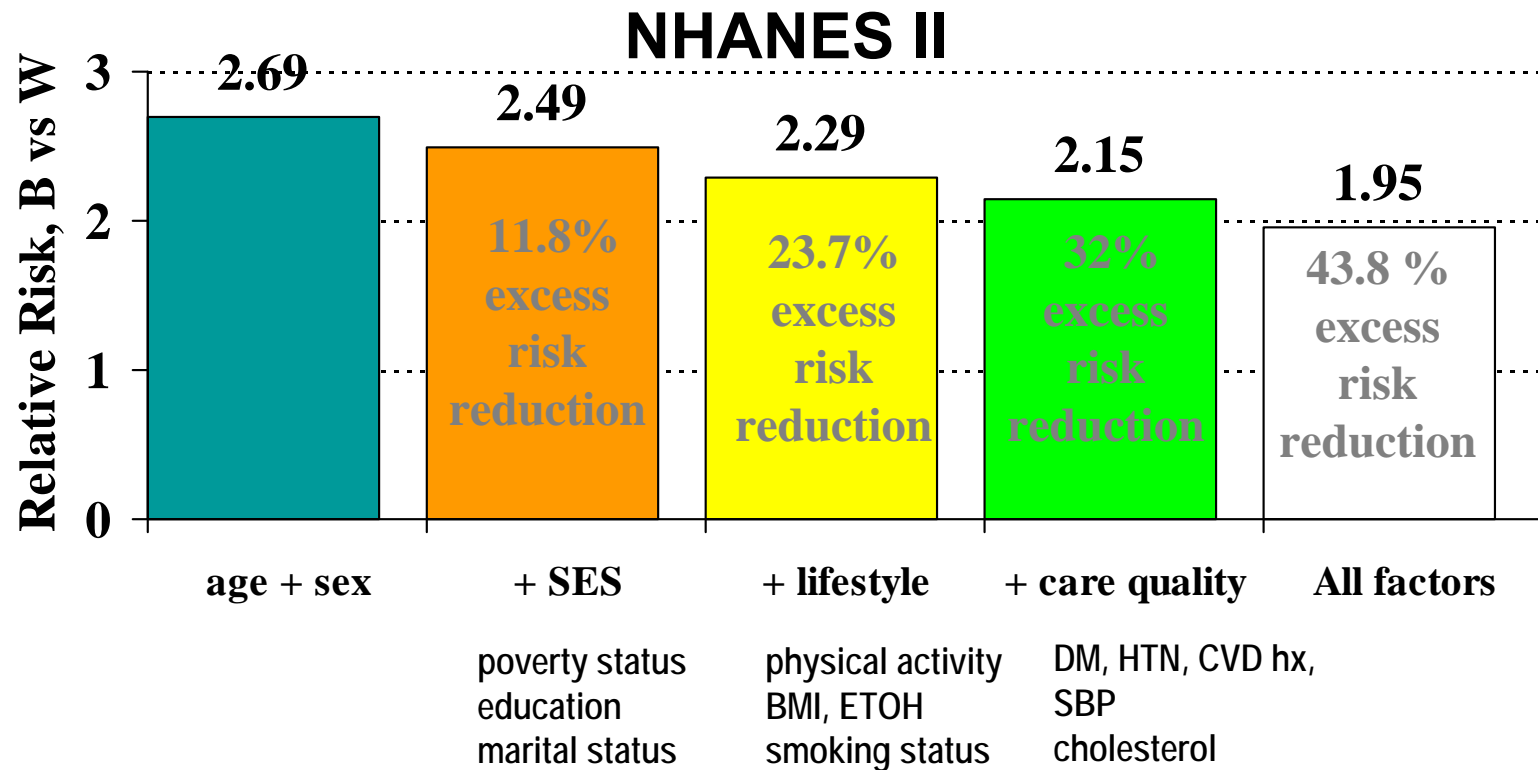
Black men and black women have higher risk of ESRD despite presence or absence of diabetes or hypertension



Xue JL, Eggers PW, Agodoa LY, Foley RN, Collins AJ. Longitudinal Study of Racial and Ethnic Differences in Developing ESRD among aged Medicare Beneficiaries. JASN 2007;18:1299-1306

Are there other factors that explain the greater rate of progression to ESRD in minorities?

Socioeconomic Status, Lifestyle and Quality of Care Factors Can Explain almost half of the 3-fold excess risk of CKD in African Americans vs Whites



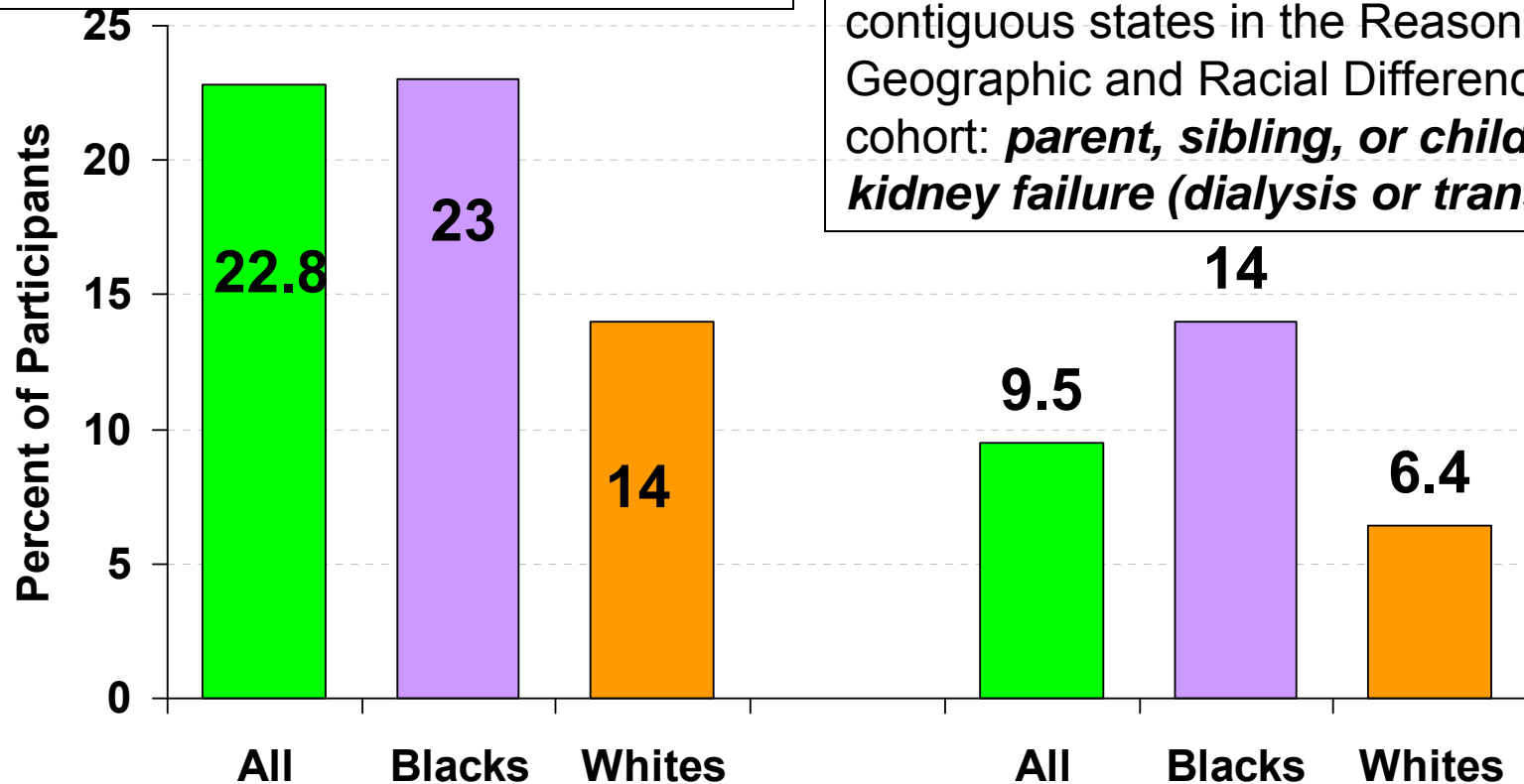
Tarver-Carr M, Powe NR, Eberhardt M, LaVeist TA, Kington RS, Coresh J, Brancati F. Excess Risk of Chronic Kidney Disease among African-American versus White Subjects in the United States: A Population-Based Study of Potential Explanatory Factors. *Journal American Society Nephrology*. 2002;13:2363-70.

Genetics? Blacks more likely to have a family history of ESRD than Whites

Of 25,883 patients starting dialysis in southeast U.S : **1st or 2nd degree relative who was also being treated for ESRD**



12,030 US residents 45 yr and older in NC, SC, GA, TN, MS AL, LA, AR and contiguous states in the Reasons for Geographic and Racial Differences in cohort: **parent, sibling, or child with kidney failure (dialysis or transplant)**



- Freedman BI, Volkova NV, Satko SG, Krisher J, Jurkovitz C, Soucie JM, McClellan WM. Population-based screening for family history of end-stage renal disease among incident dialysis patients. *Am J Nephrol.* 2005 ;25(6):529-35.
- McClellan W, Speckman R, McClure L, Howard V, Campbell RC, Cushman M, Audhya P, Howard G, Warnock DG. Prevalence and Characteristics of a Family History of ESRD among Adults in the US Population. *J Am Soc Nephrol.* 2007 Apr;18(4):1344-52.

Genetics?

- APOE variation predicts kidney disease progression:

Hsu CC, Kao WH, Coresh J, Pankow JS, Marsh-Manzi J, Boerwinkle E, Bray MS. Apolipoprotein E and progression of chronic kidney disease. JAMA. 2005;293:2892-2899

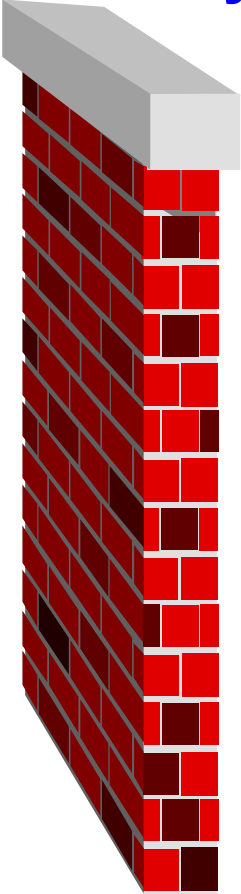
- e2 allele is higher in frequency in blacks than in whites
- e2 allele associated with increased incident CKD in both blacks and whites
- However, the allele frequency difference does not account for difference in disease progression:
 - APOE is just one allele of many susceptible alleles?
 - Protective allele (e4) is also higher in frequency in blacks

Potential Reasons for Disparities in Initiation and Progression of CKD

- demographic -- age
- biologic and clinical factors
 - diabetes, hypertension, obesity, dyslipidemia, autoimmune diseases, infections, stones, obstruction reduced kidney mass, hyperfiltration states, higher level of proteinuria, genetics
- socioeconomic status
- family history
- environmental factors
- psychosocial and cultural factors
- health risk behavior and lifestyles
- **access to & quality of health care**

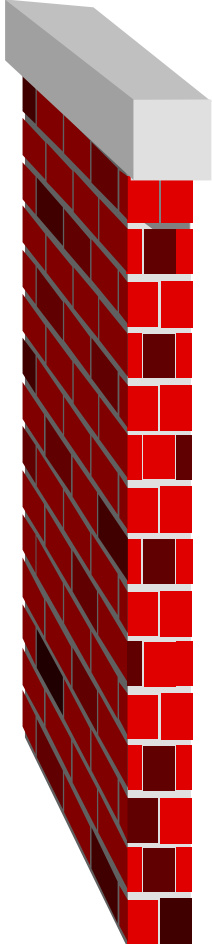
Barriers Creating Health Care Disparities

System

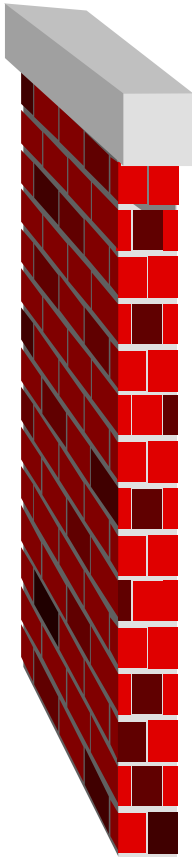


- Lack of health insurance
- Availability of providers
- **Type of providers and their resources**
- Location of services
- Organization of care

Patient



Provider



Powe NR. Let's get serious about racial and ethnic disparities. *Journal of the American Society of Nephrology* 2008 (in press)

Blacks are treated by different physicians than whites and their physicians have less access to important clinical resources

	White Pts	Black Pts
Physician Characteristics	Percent of Physicians	
Race: white	85.3	59.7
black	0.7	22.4
asian	10.3	15.7
Board certified	86.1	77.4
Access to services		
- high quality specialists	82.1	76.0
- diagnostic imaging	83.4	75.6
- hospital admission	63.0	51.5
- ancillary services	72.3	63.4
Able to provide high quality of care	80.7	72.2
Good communication with subspecialists	88.5	85.9

When whites and minorities are admitted (for same reason or hospital procedure) they generally receive the same quality of care

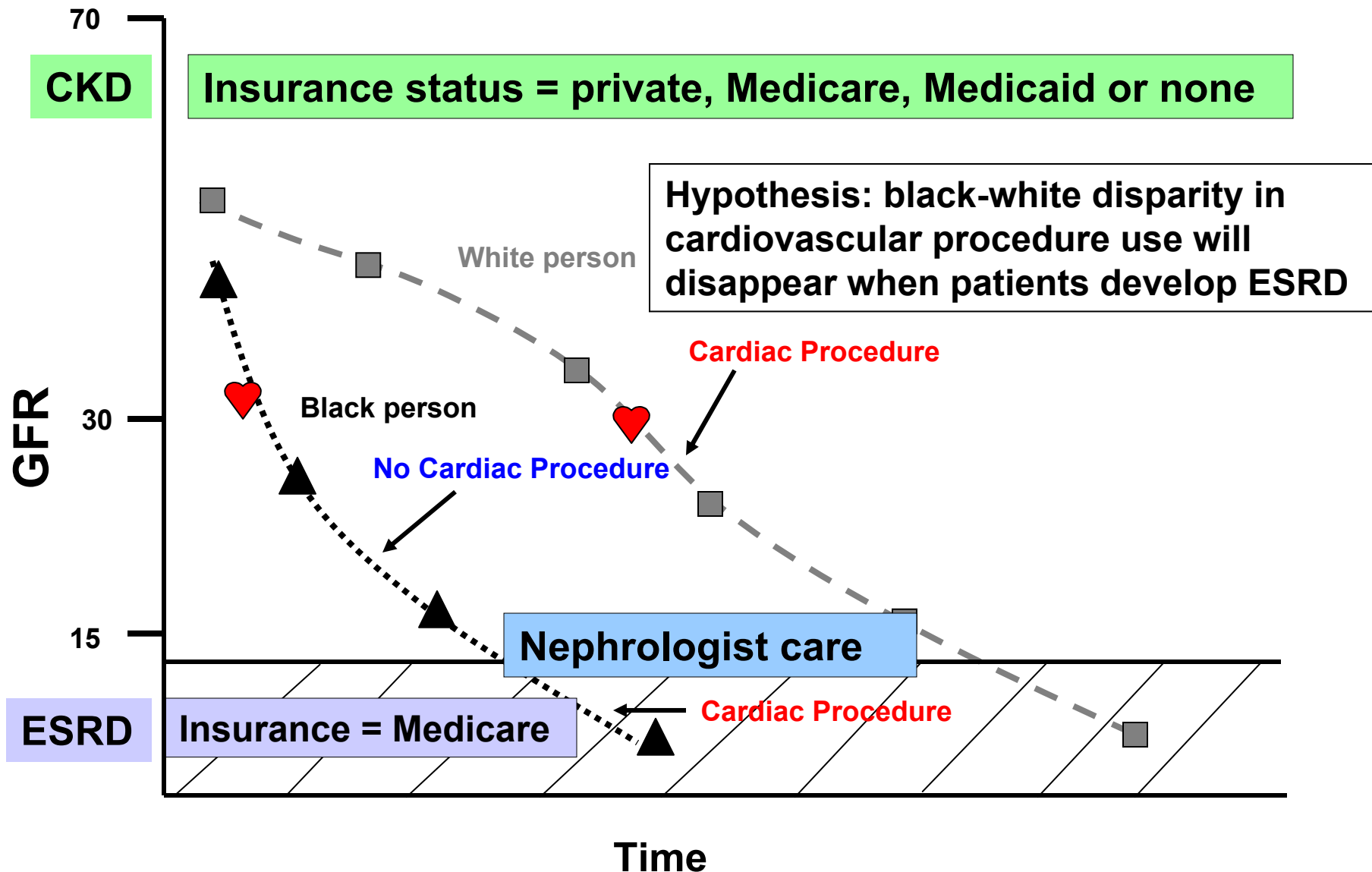
- Design: National, cross-sectional study
- Subjects: White, African American, Hispanic and Asian patients with an inpatient stay (13 states over three years)
- Outcome: Risk adjusted quality and patient safety indicators
- Results: In the same hospital, risk adjusted quality indicators were not worse for minorities than whites. Few hospitals provide lower quality of care to minorities than to whites.
 - African Americans and Hispanics had higher rates of adverse events than whites in less than 5% of hospitals -- exception decubitus ulcer for African Americans (13%)
 - Asians had higher adverse event rates than whites for obstetrical trauma, vaginal birth (18% of hospital)

Gaskin DJ, Spencer CS, Richard P, Anderson GF, Powe NR, Laveist TA. Do hospitals provide lower-quality care to minorities than to whites? Health Affairs 2008; 27:518-27.

Does having a system of care matter?

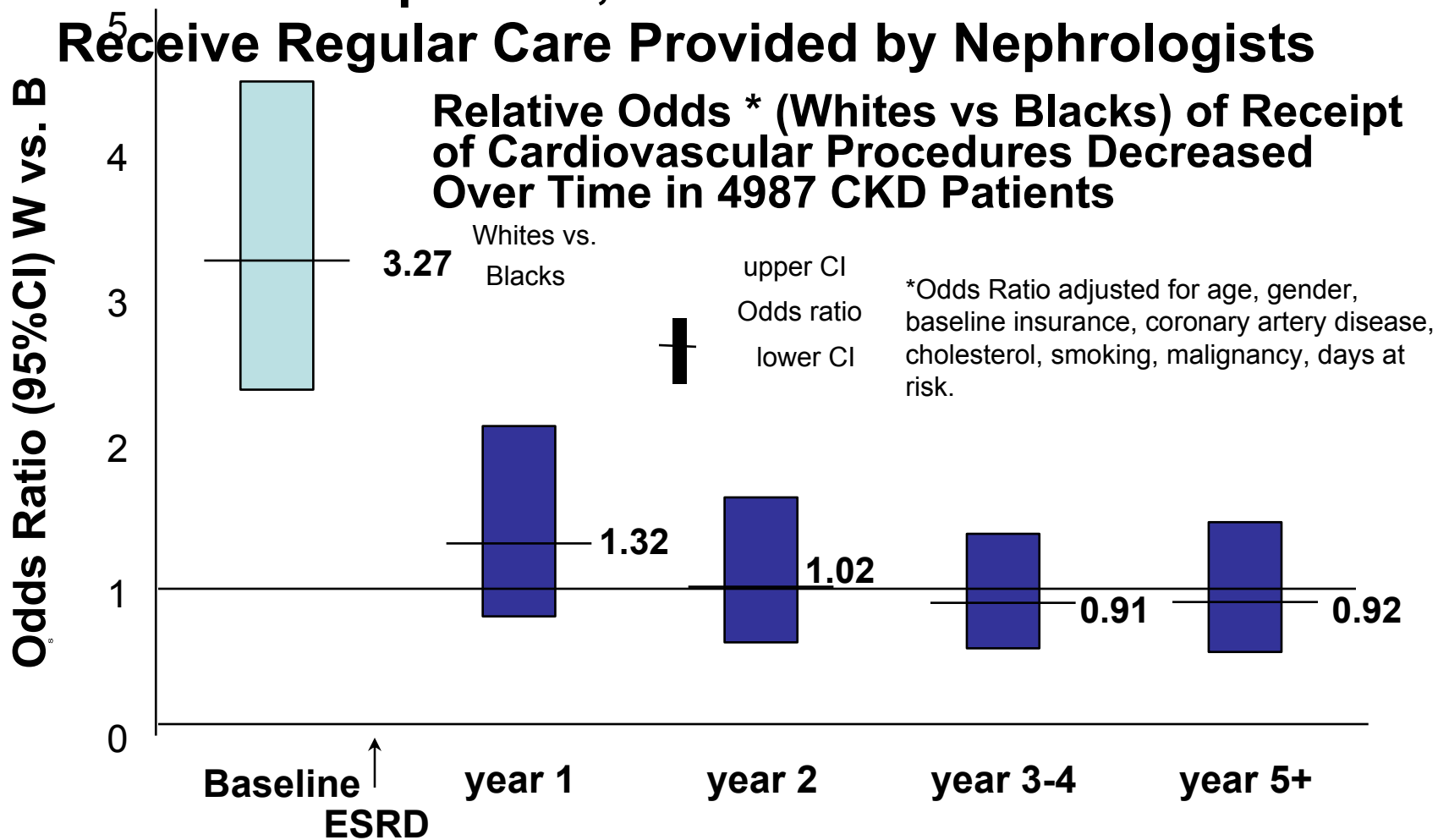
- Hypothesis: black-white disparity in cardiovascular procedure use seen in the general population will disappear when patients develop ESRD
 - With ESRD: Medicare insurance, regular provision of care by nephrologist and possibly stricter criteria for CABG in more ill patients.
- Study design: national retrospective cohort study of 3152 white and 1835 adult black incident ESRD patients in 1986-7 (5% national random sample)
- Follow-up: up to 7 years, transplantation, or death
- Data collected: cardiovascular procedure use before ESRD onset (and Medicare coverage) and after

Progression of Chronic Kidney Disease



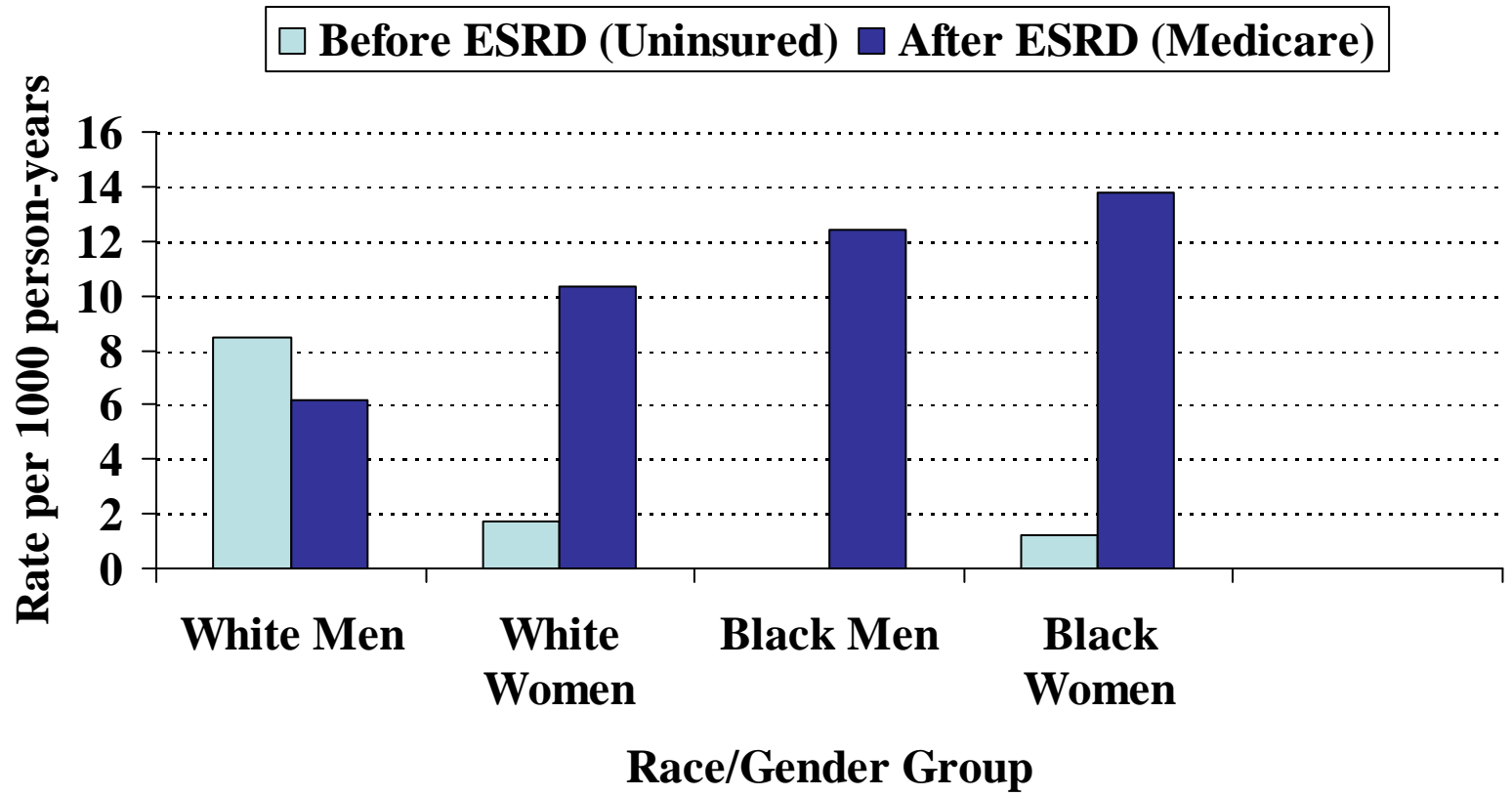
Disparities in Cardiovascular Procedure Use are Eliminated When:

Patients Develop ESRD, Gain Medicare Insurance and Receive Regular Care Provided by Nephrologists



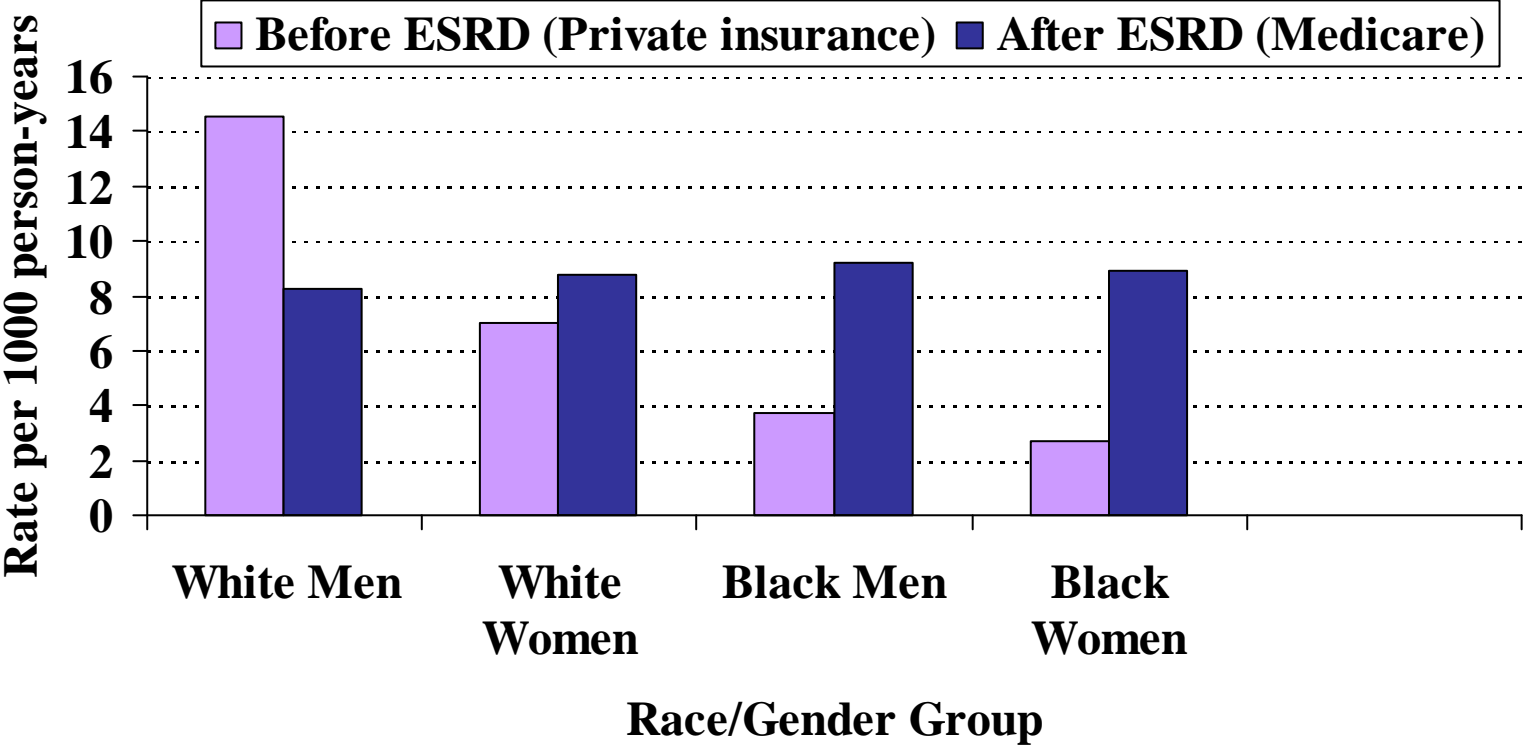
Daumit GD, Hermann JA, Coresh J, Powe NR. Cardiovascular Procedure Use Among Blacks and Whites: A Seven-Year National Study in Patients with Renal Disease *Annals of Internal Medicine* 1999;130:173-182

Rates of Cardiovascular Procedure Use Increase Among Blacks Who Were Uninsured Prior to ESRD



Daumit GD, Hermann JA, Coresh J, Powe NR. Cardiovascular Procedure Use Among Blacks and Whites: A Seven-Year National Study in Patients with Renal Disease *Annals of Internal Medicine* 1999;130:173-182

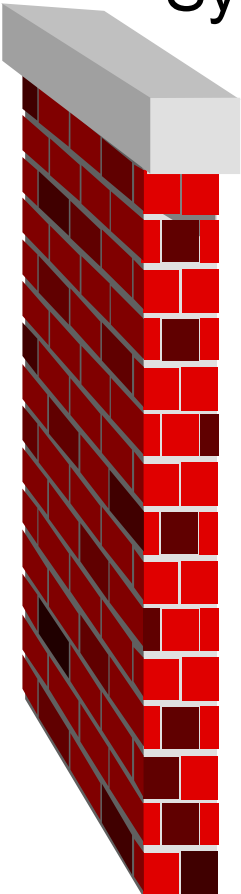
Rates of Cardiovascular Procedure Use Also Increase Among Black Patients Who Were Privately Insured Prior to ESRD



Daumit GD, Hermann JA, Coresh J, Powe NR. Cardiovascular Procedure Use Among Blacks and Whites: A Seven-Year National Study in Patients with Renal Disease *Annals of Internal Medicine* 1999;130:173-182

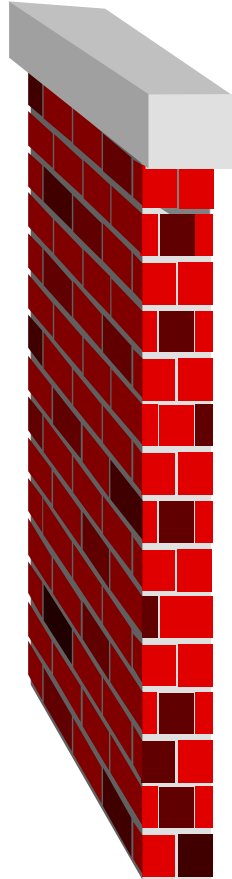
Barriers Creating Health Care Disparities

System



- Lack of health insurance
- Availability of providers
- Type of providers and their resources
- Location of services
- Organization of care

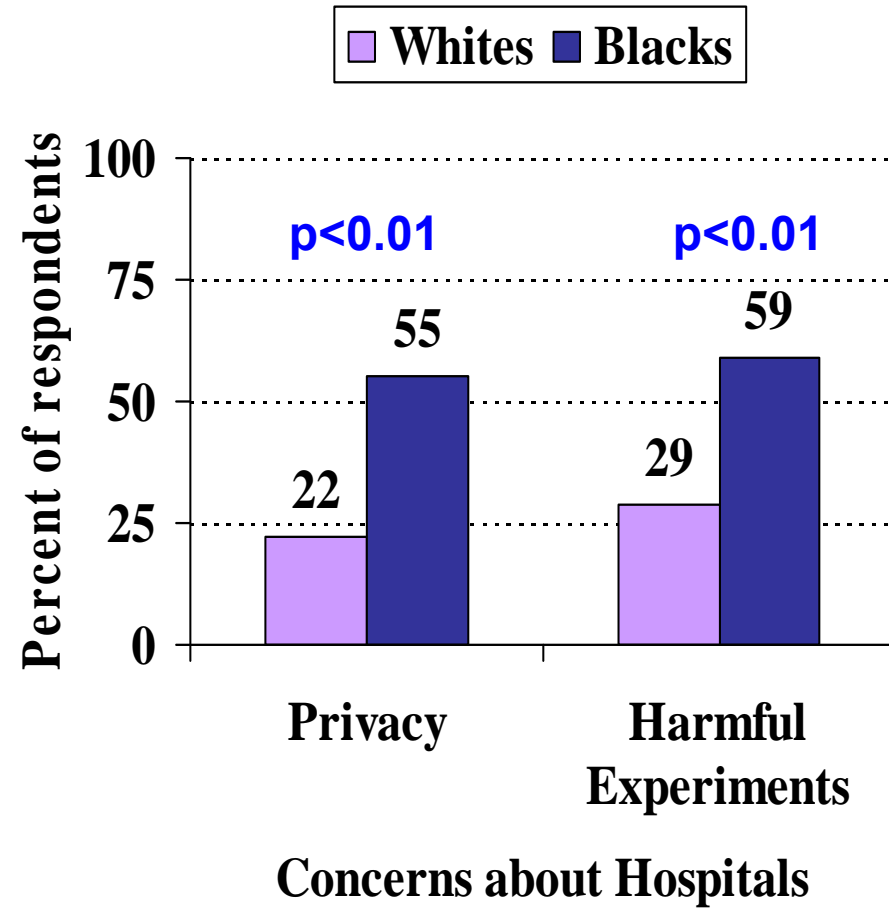
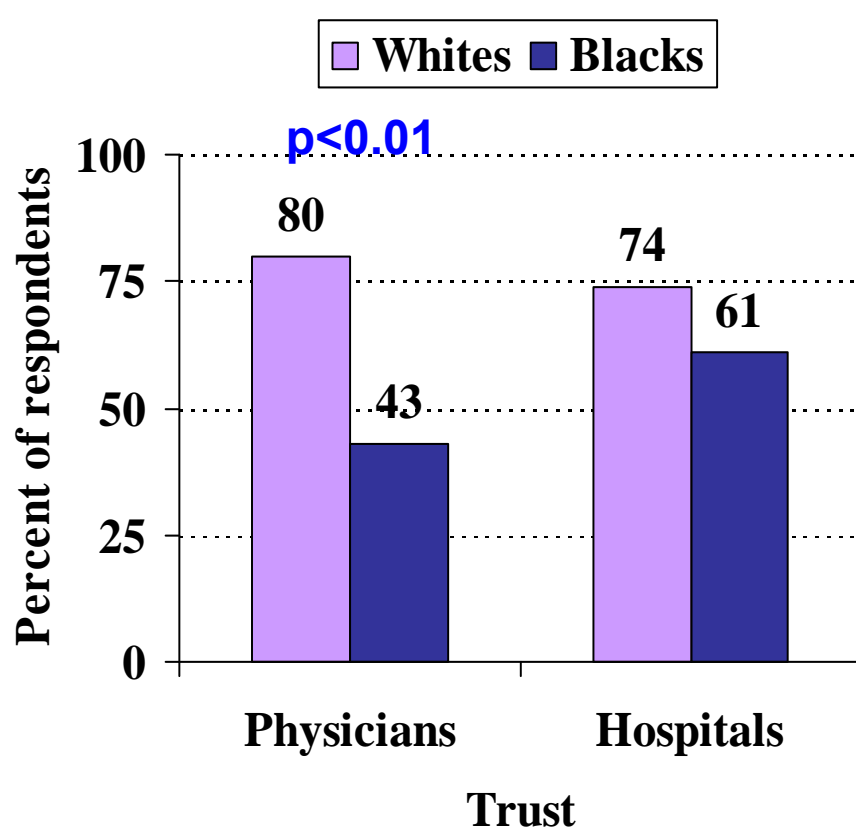
Patient



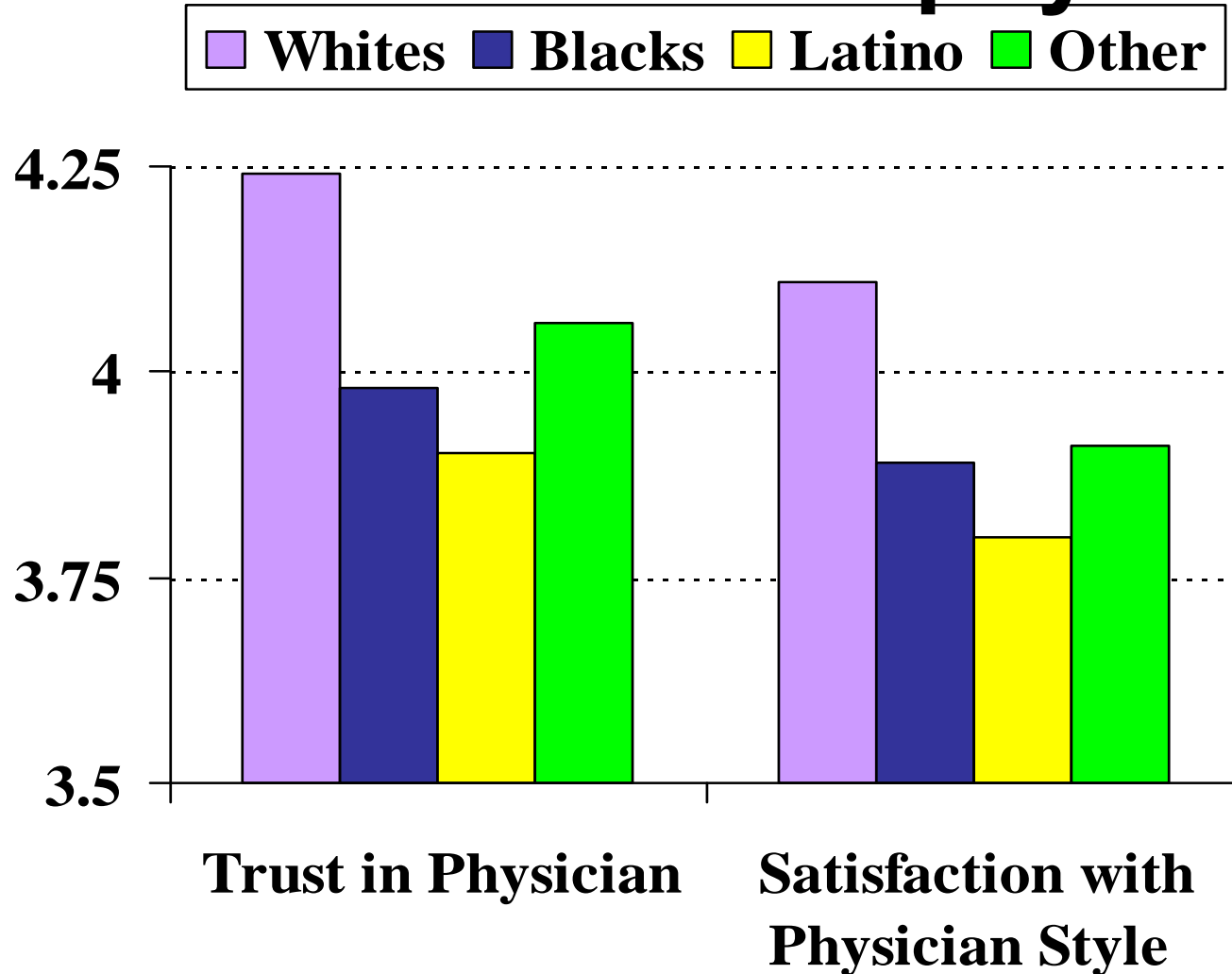
- Knowledge
- Attitudes
- Cultural beliefs
- Health behaviors
- Language
- Health Literacy
- Social support
- Religious beliefs
- Fear
- Self-efficacy
- Preferences
- Psychosocial
- Socioeconomic status
- Homelessness
- **Trust**

Powe NR. Let's get serious about racial and ethnic disparities. *Journal of the American Society of Nephrology* 2008 (in press)

African Americans have less trust in physicians and hospitals



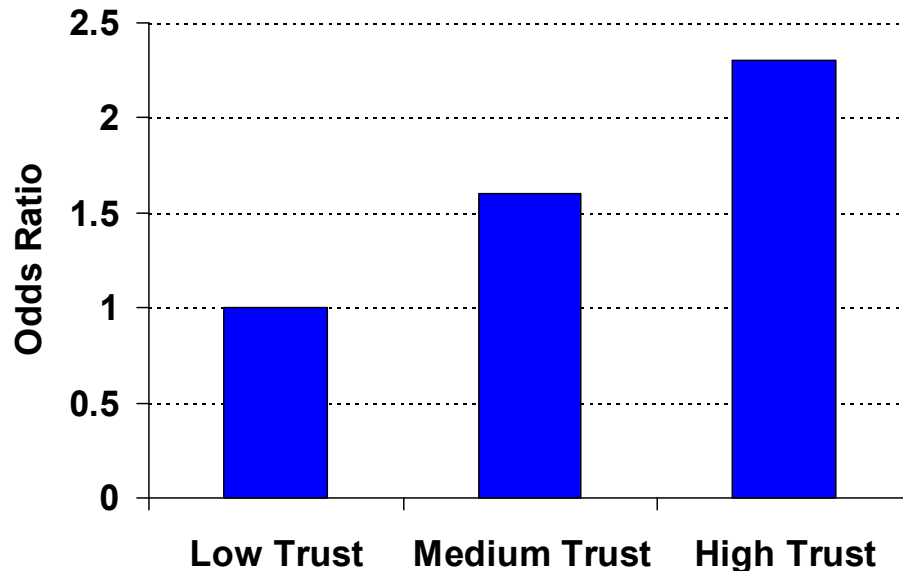
Latinos also have less trust in and satisfaction with physicians



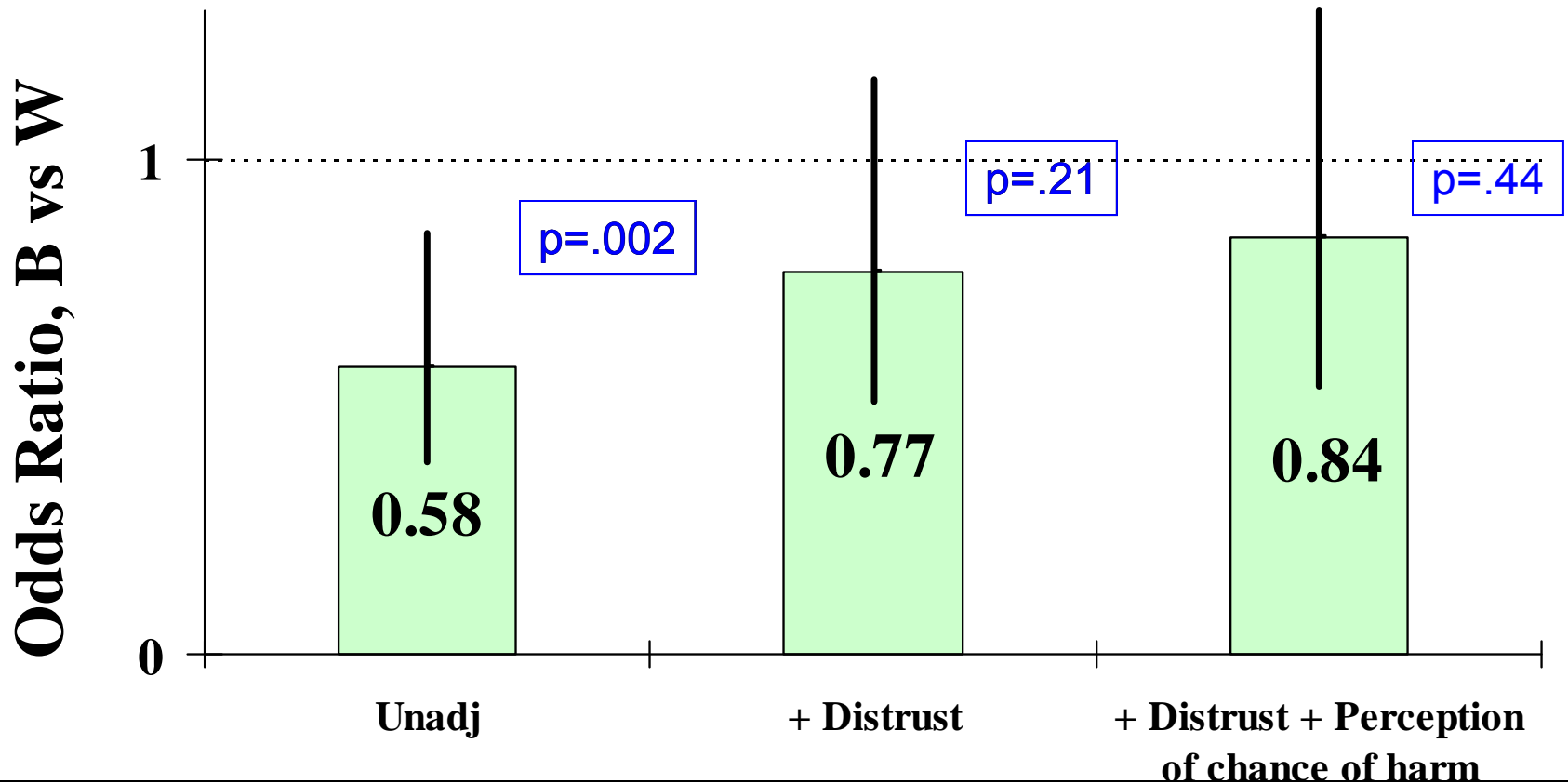
Doescher M et al. *Arch Fam Med* 2000;9:1156-63.

Trust: Why Do We Care?

- Because it is linked to quality of care
 - patient adherence (Safran 1998 *J Fam Pract* and Hall 2002, *HSR*)
 - satisfaction (Safran 1998 *J Fam Pract* and Hall 2002, *HSR*)
 - continuity of care (Kao 1998, *JGIM*)
 - self-rated health (Safran 1998 *J Fam Pract*)
 - receipt of preventive services (O'Malley 2004 *Prev Med*)



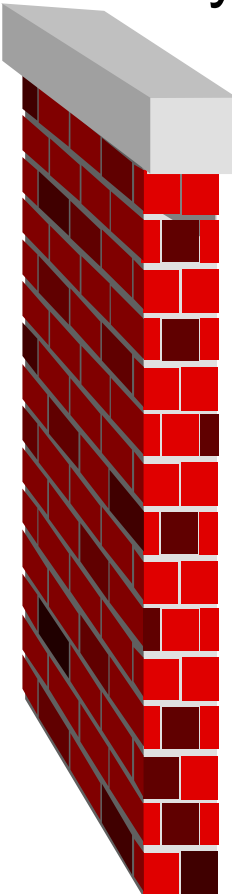
Trust and Perceived Chance of Harm Explain *Willingness of Minorities to Participate in a Clinical Trial*



Braunstein JB, Sherber NS, Schulman SP, Ding EL, Powe NR. Race, medical researcher distrust, perceived harm, and willingness to participate in cardiovascular prevention trials. *Medicine*. 2008; 87:1-9.

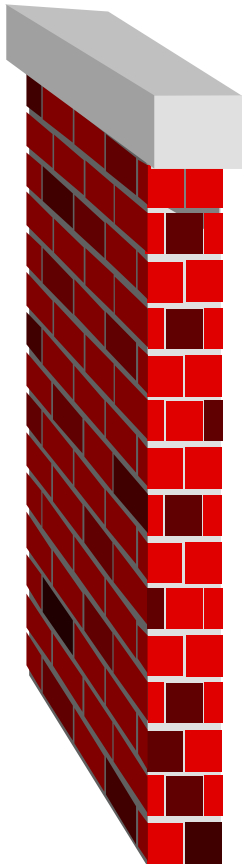
Barriers Creating Health Care Disparities

System



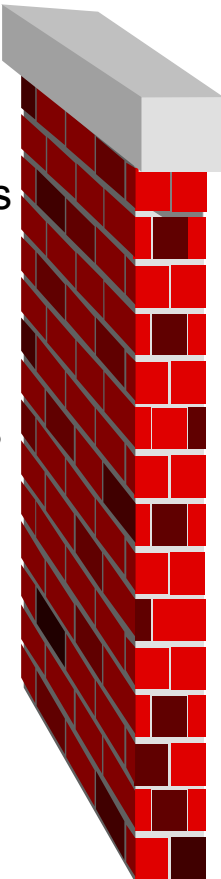
- Lack of health insurance
- Availability of providers
- Type of providers and their resources
- Location of services
- Organization of care

Patient



- Knowledge
- Attitudes
- Cultural beliefs
- Health behaviors
- Language
- Health Literacy
- Social support
- Religious beliefs
- Fear
- Self-efficacy
- Preferences
- Psychosocial
- Socioeconomic status
- Homelessness
- Trust

Provider

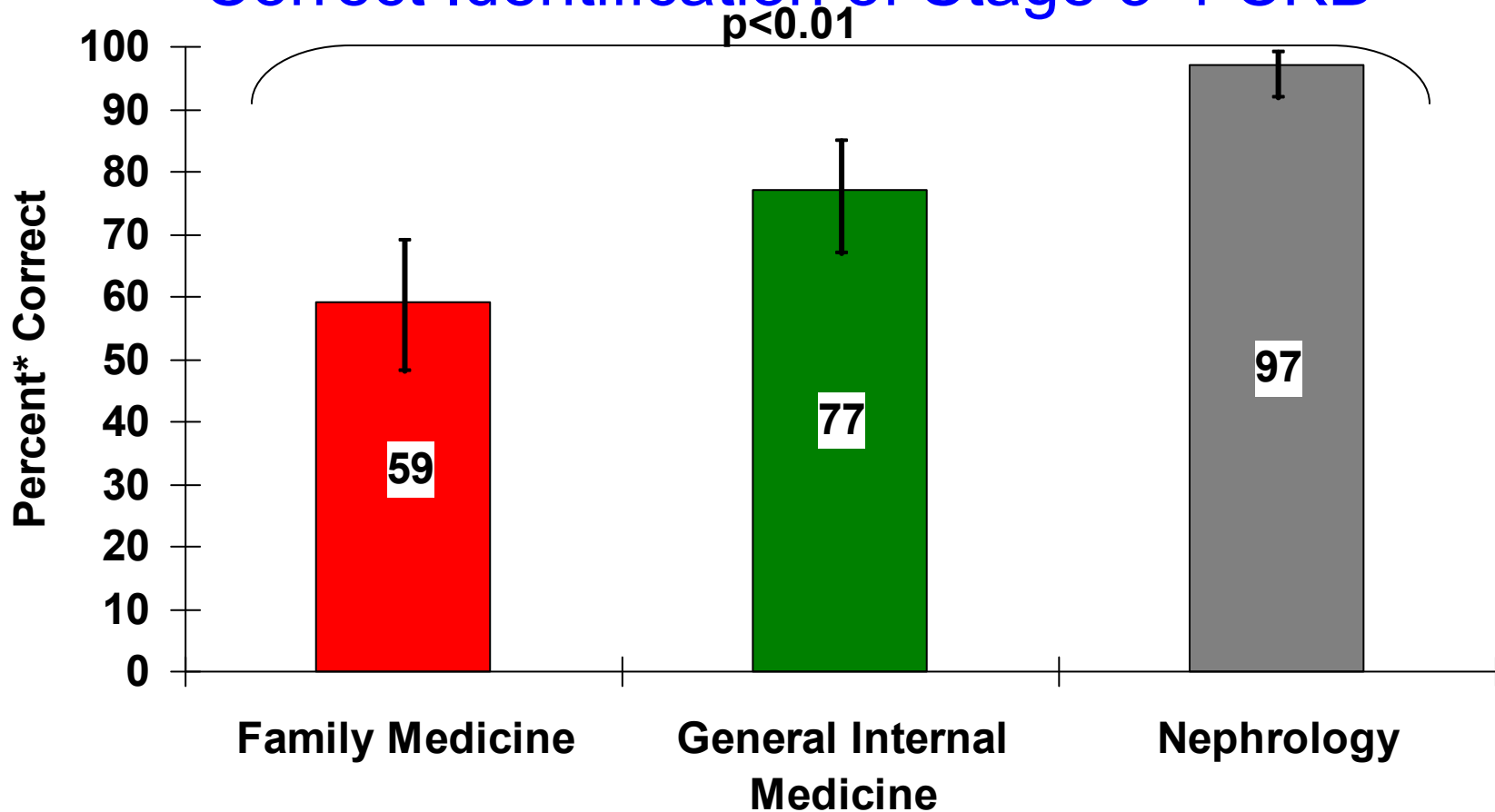


- Knowledge
- Attitudes and bias
- Lack of technical or interpersonal skills
- Communication
- Decision-making (participatory) style
- Patient-centered care
- Physician social concordance with patient

Powe NR. Let's get serious about racial and ethnic disparities. *Journal of the American Society of Nephrology* 2008 (in press)

CKD is Not Being Recognized

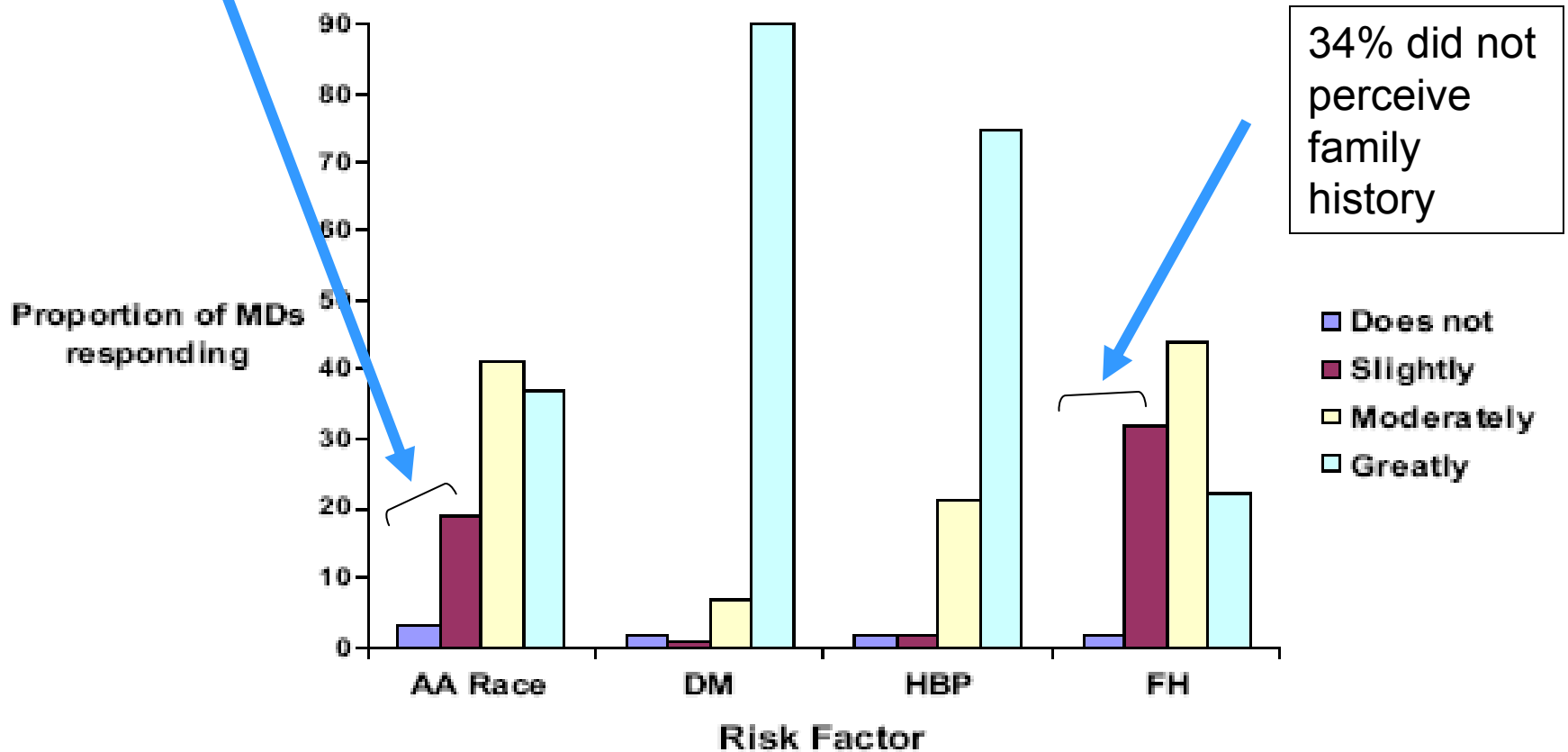
Correct Identification of Stage 3-4 CKD



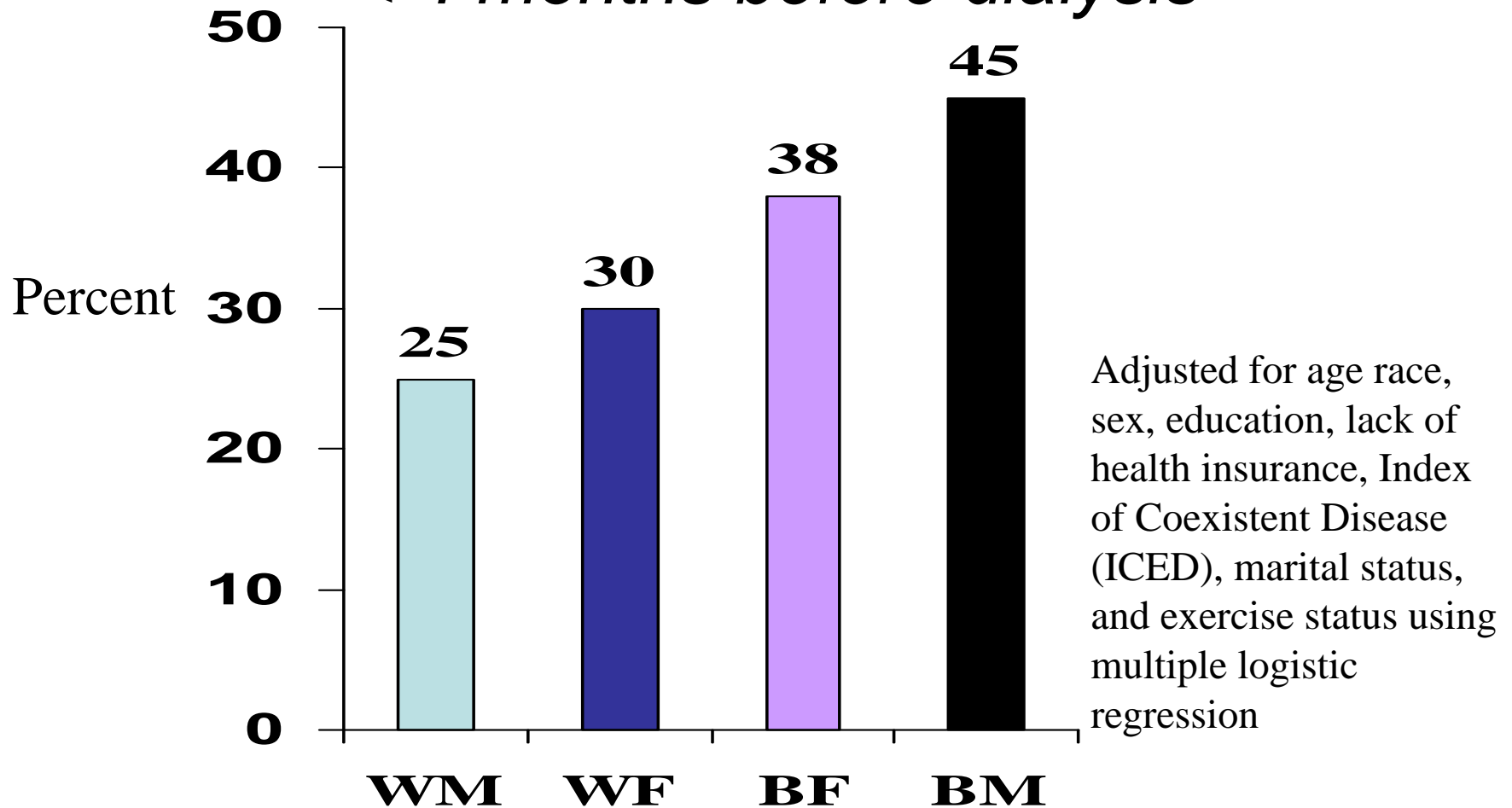
*Adjusted for: practice setting, clinical time, years in practice, patient scenario (race, diabetes or hypertension), census region

Boulware LE, Troll MU, Jaar BG, Myers DI, Powe NR. Identification and referral of patients with progressive CKD: a national study. Am J Kidney Dis. 2006 ;48(2):192-204.

22% of Primary Care Physicians Did Not Perceive African American Race as a CKD Risk Factor

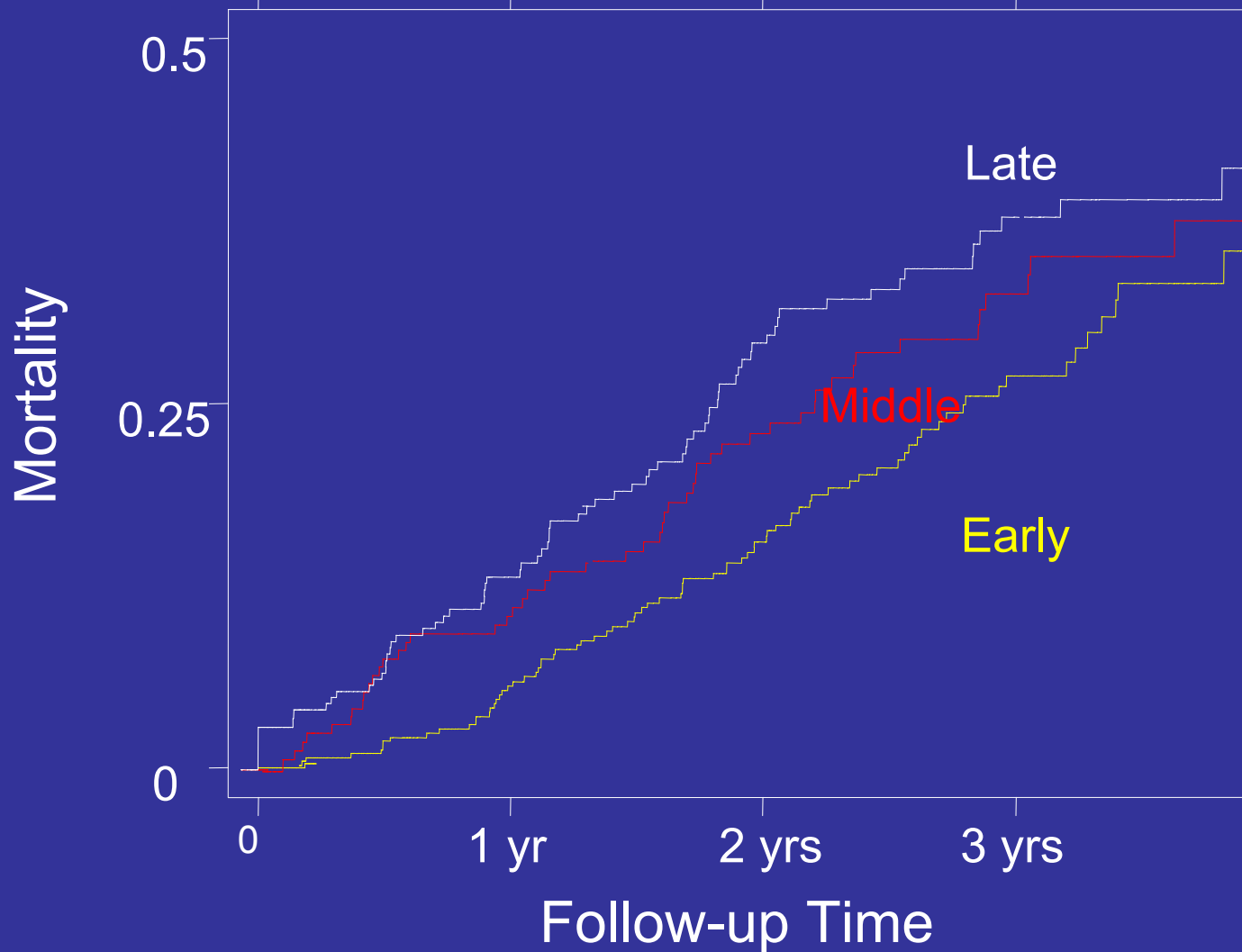


Over One Third of Black Dialysis Patients Receive a Late Evaluation by a Nephrologist < 4 months before dialysis



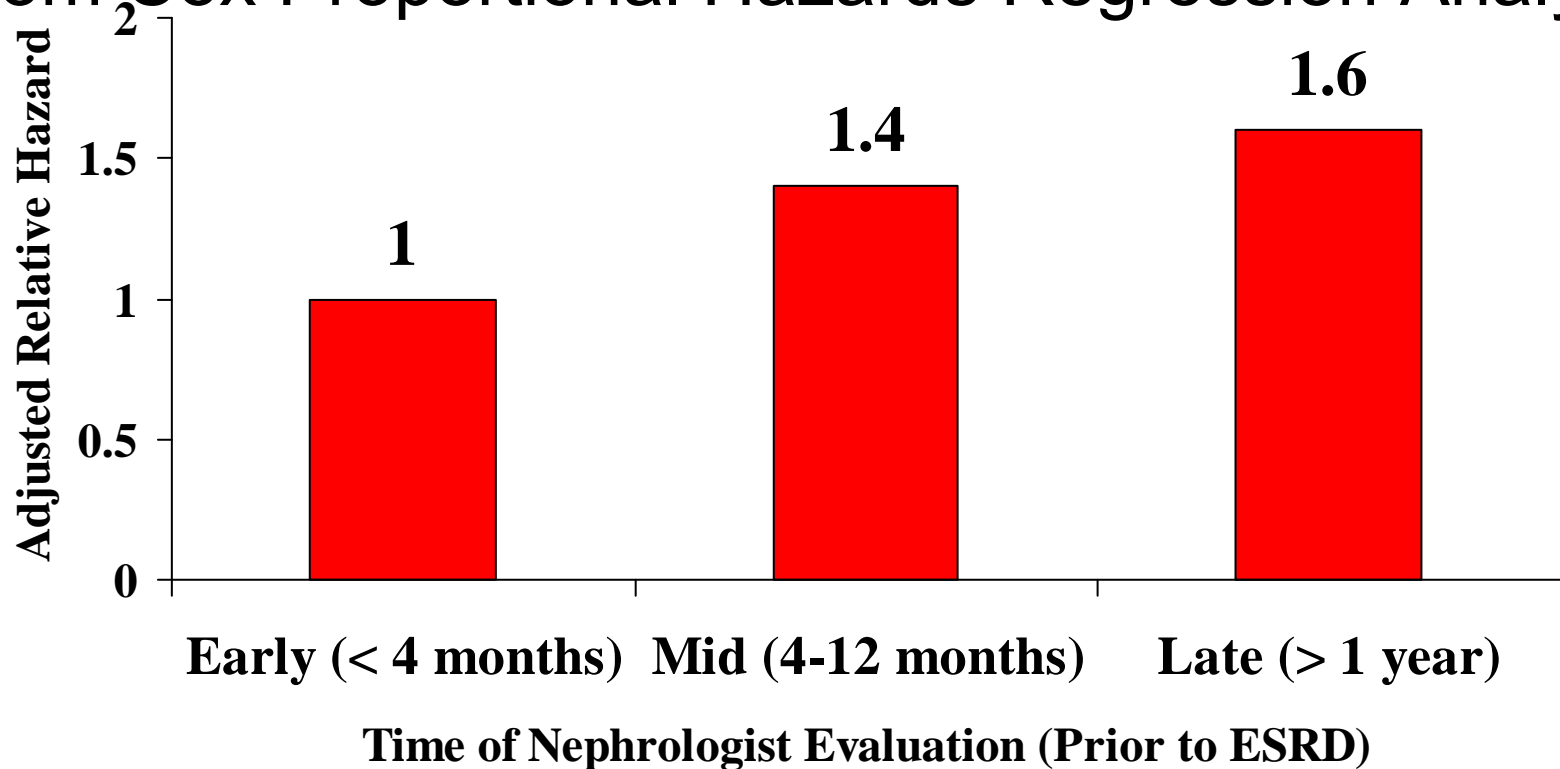
Kinchen KS, Sadler J, Fink N, Brookmeyer R, Klag, M, Levey A, Powe N. The Timing of Specialist Evaluation in Chronic Kidney Disease and Mortality *Annals of Internal Medicine* 2002;137:479-86.

Late Evaluation is Associated with Greater Mortality



Late evaluation associated with greater mortality on dialysis, especially for blacks

from Cox Proportional Hazards Regression Analysis

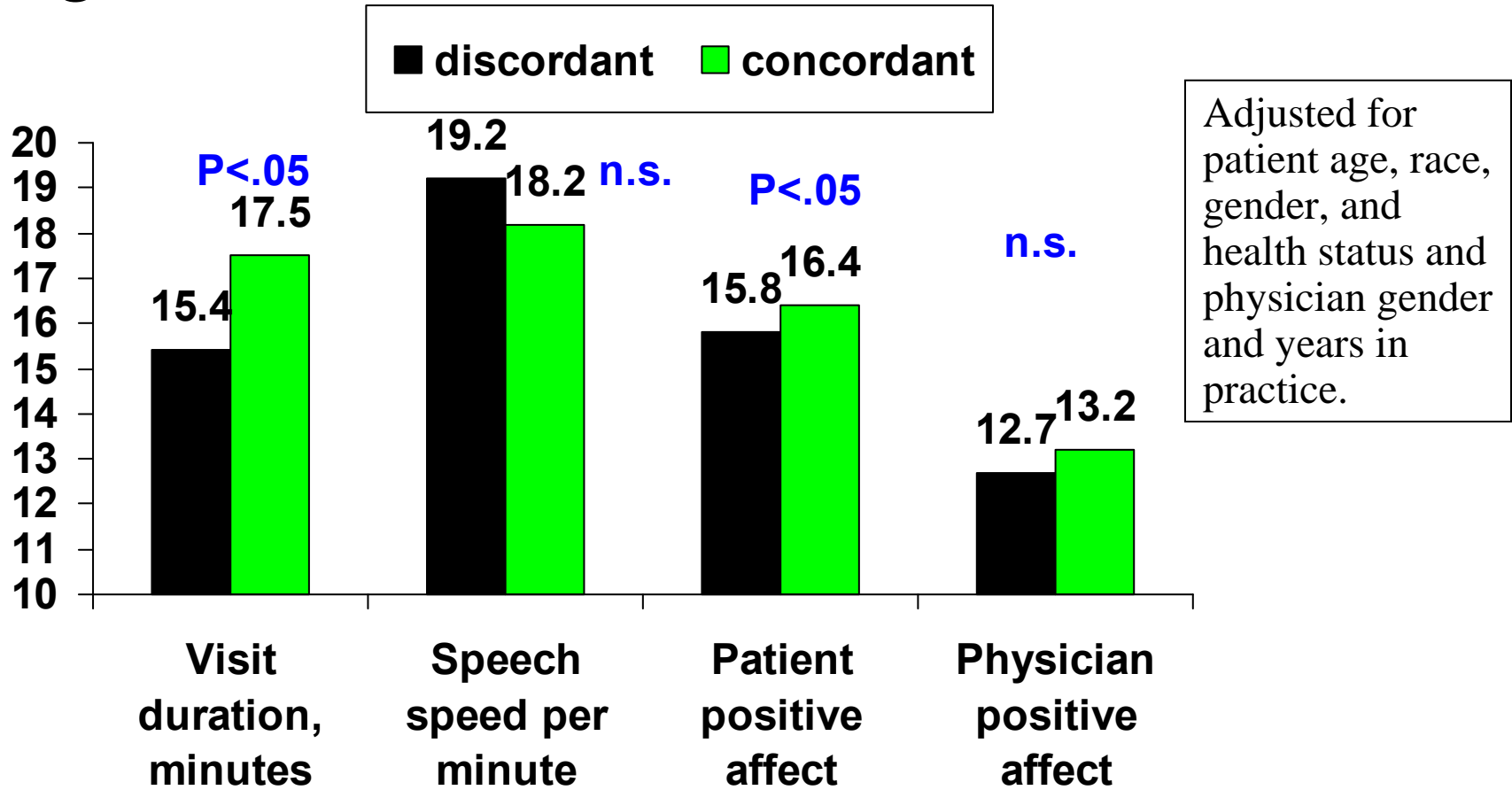


Kinchen KS, Sadler J, Fink N, Brookmeyer R, Klag, M, Levey A, Powe N. The Timing of Specialist Evaluation in Chronic Kidney Disease and Mortality *Annals of Internal Medicine* 2002 ;137:479-86

Adjusted for modality, demographic factors, SES factors, years smoking, exercise status, ICED.

Patient-Physician Communication?

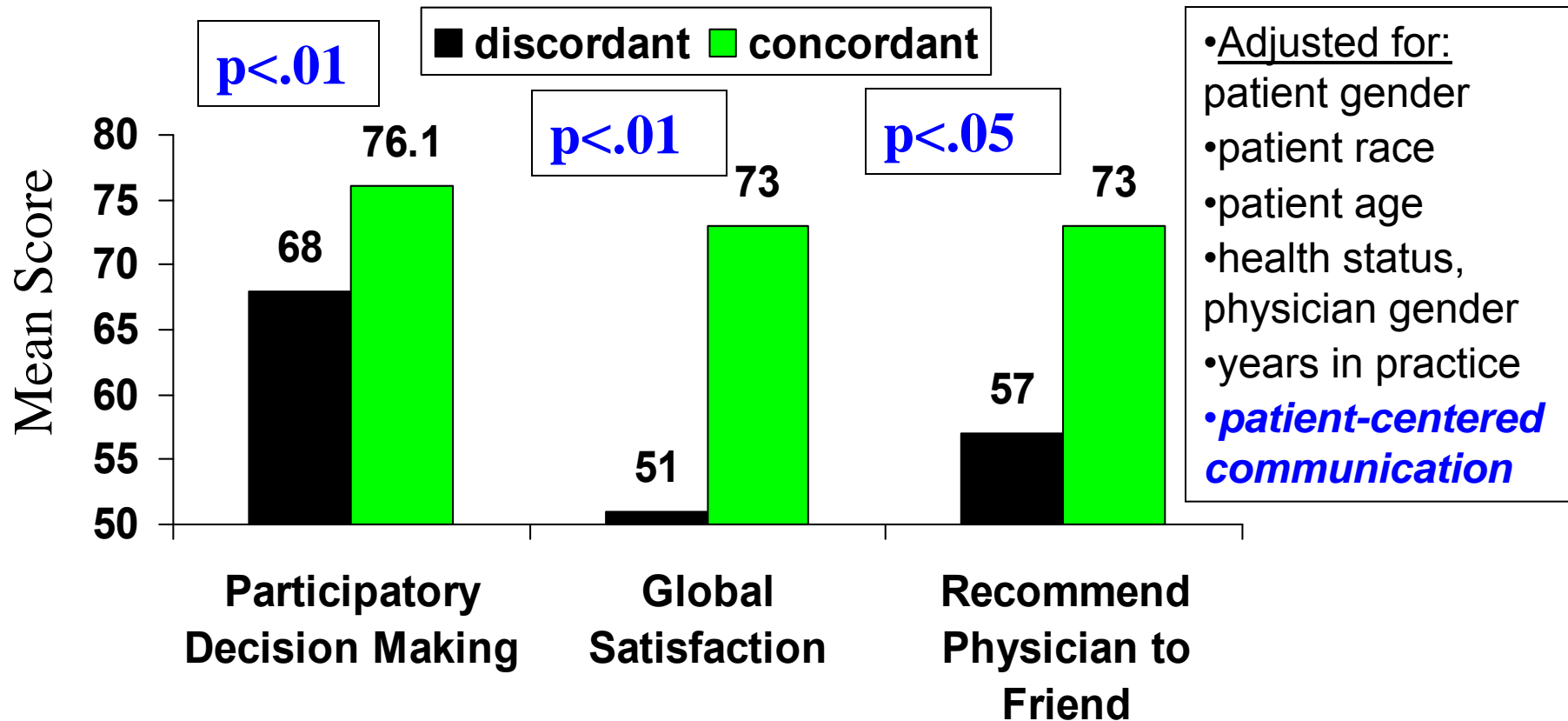
Race-Concordant Relationships Have Longer Visits & More Positive Patient Affect



Cooper L, Roter D, Johnson R, Ford D, Steinwachs D, Powe N. Patient-centered communication, ratings of care and concordance of patient & physician race. *Ann Intern Med.* 2003;139: 907-15.

Patients in Race-Concordant Relationships Rate Their Physicians Better

Regardless of Communication!



Cooper L, Roter D, Johnson R, Ford D, Steinwachs D, Powe N. Patient-centered communication, ratings of care and concordance of patient and physician race. *Ann Intern Med.* 2003;139: 907-15.

What's left to do?

Unfortunately, we have not made much progress.

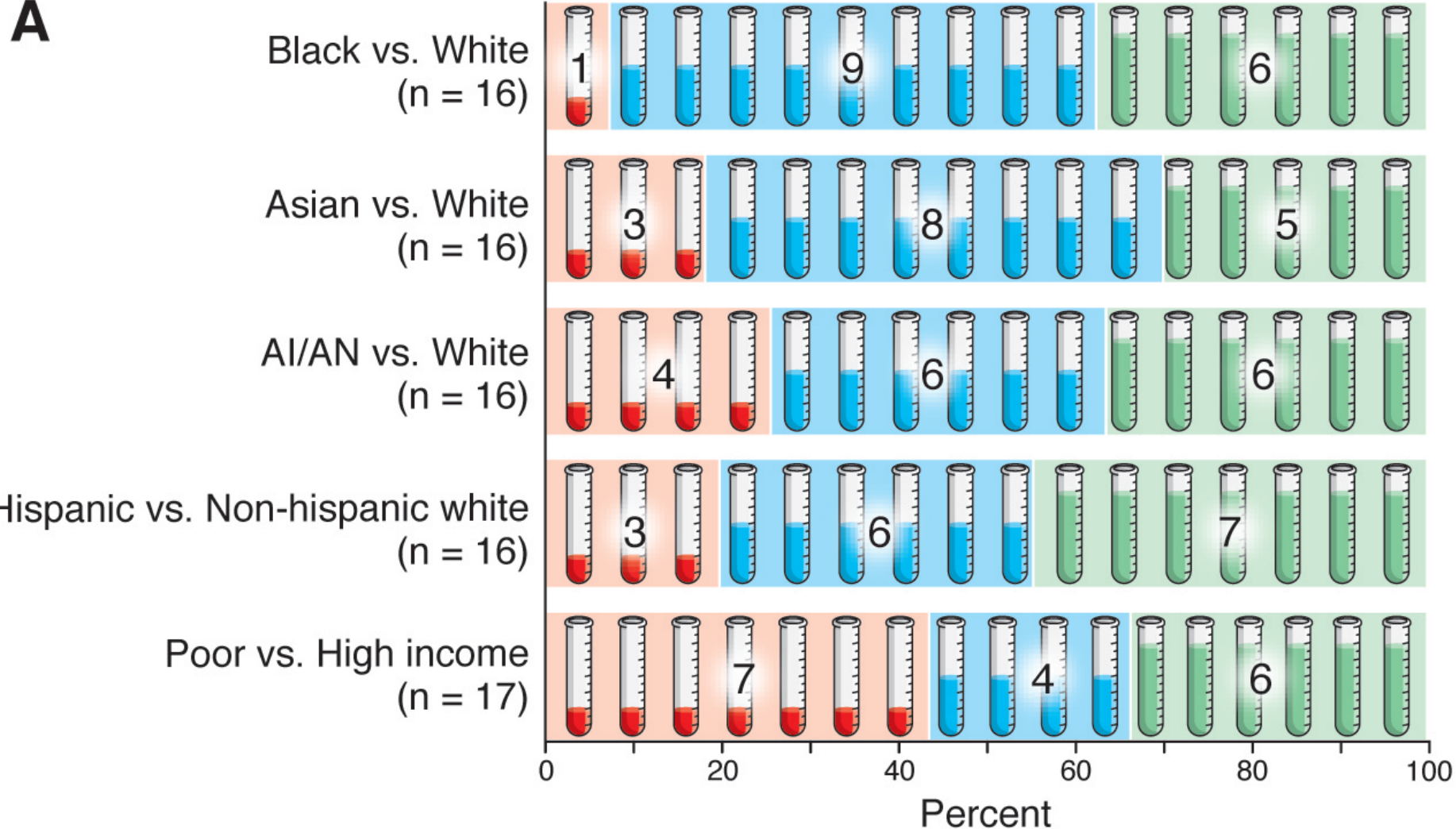
There is little rigorous evidence, either nationally or locally, that current efforts to eliminate racial disparities in health care are successful.

2007 National Health Disparities Report

Change over time in core quality of care measures for vulnerable populations

Worsening Same Improving

A



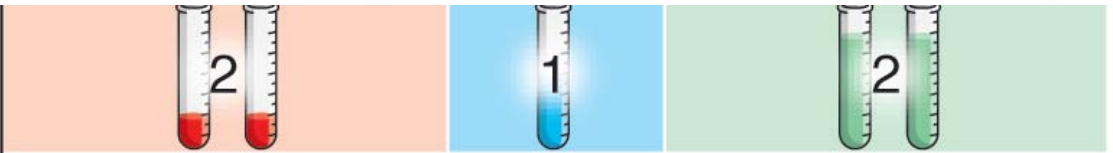
2007 National Health Disparities Report

Change over time in core access to care measures for vulnerable populations

B

Worsening Same Improving

Black vs. White
(n = 5)



Asian vs. White
(n = 5)



AI/AN vs. White
(n = 5)



Hispanic vs. Non-hispanic white
(n = 5)



Poor vs. High income
(n = 5)



0 20 40 60 80 100

Percent

Interventions to improve the quality of or reduce disparities in healthcare for minorities:

A systematic review

- **27 trials identified** -- randomized or concurrent controlled
- Diseases/conditions
 - **chronic kidney disease 1 trial**
 - asthma, respiratory tract infect, emerg med systems and advance directives, **1 trial each**; depression & alcohol abuse **2 trials**; cervical cancer screen **6 trials**; breast cancer screening **11 trials**
- Providers targeted
 - Mostly physicians **25 trials**; primary care settings **26 trials**
- Patients
 - > 50% African American **19 trials**; > 50% Hispanic **2 trials**; diverse groups **6 trials**
- Intervention tailored specifically for minorities **2 trials only**
- **Outcomes:** healthcare processes -- use of services **7 trials** -- appropriateness of care **18 trials**; quality of providers **9 trials**; patient adherence **4 trials**; efficacy of treatment **1 trial**; patient health status **7 trials**; patient ratings of care **3 trials**

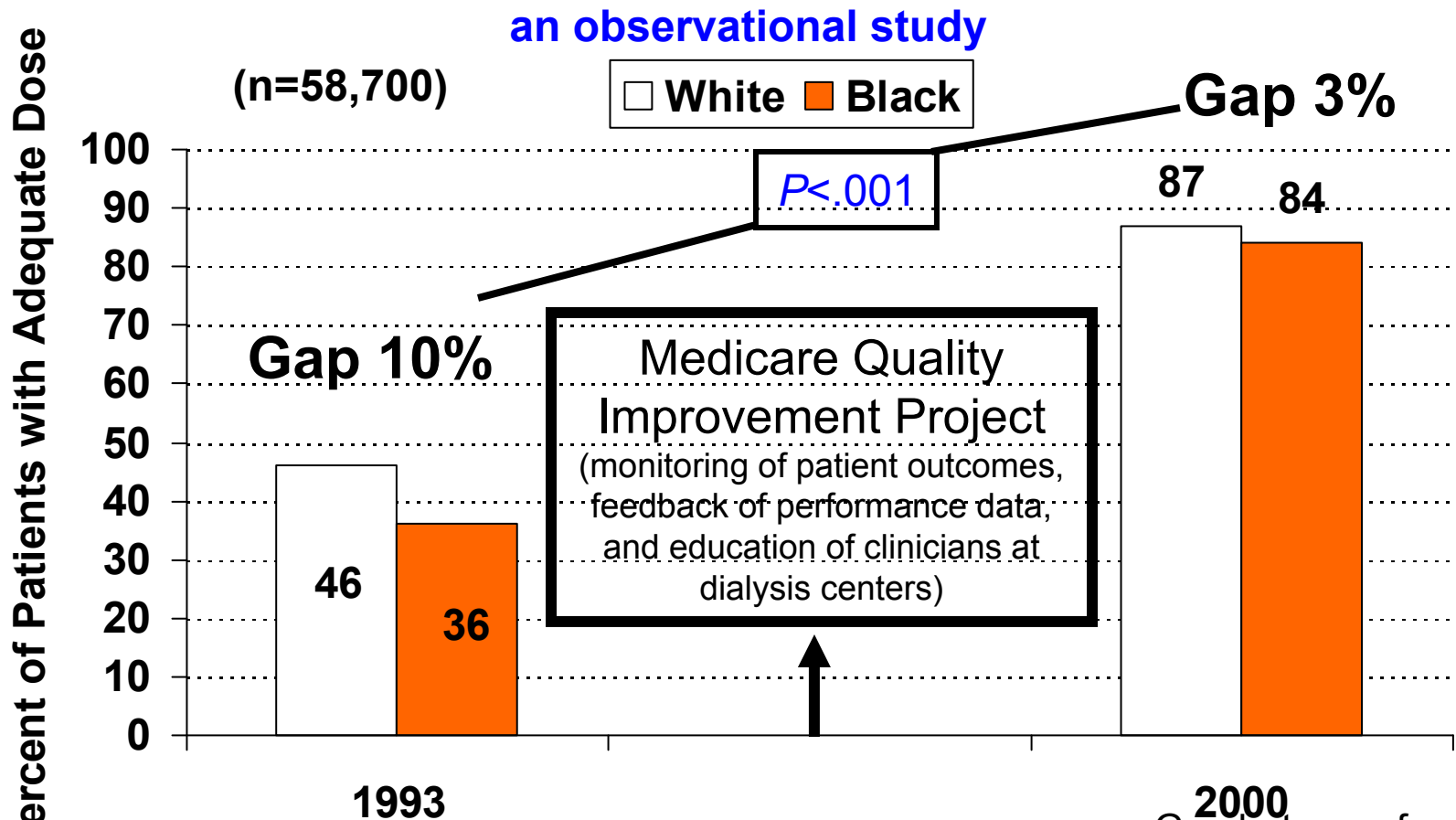
Quality Improvement Strategy Results in 27 Controlled Studies

Favorable results

- provider reminder system for provision of standardized services **10 of 10 trials**
 - bypassing the physician to offer preventive services directly to patients **2 of 2 trials**
 - provider education alone **2 of 2 trials**
 - use of a structured questionnaire to assess health behaviors **1 of 1 trial**
 - use of remote simultaneous translation **1 of 1 trial**
-
- Nephrology consultation in CKD--**negative trial**

Beach MC, Cooper LA, Robinson KA, Price EG, Gary TL, Jenckes MW, Gozu A, Smarth C, Palacio A, Feuerstein CJ, Bass EB, Powe NR. *Strategies for Improving Minority Healthcare Quality*. Agency for Healthcare Research and Quality. Rockville, MD January 2004. also BMC Public Health. 2006; 6:104.

Quality Improvement Efforts in Hemodialysis Care were Associated with Reductions in Race Disparities

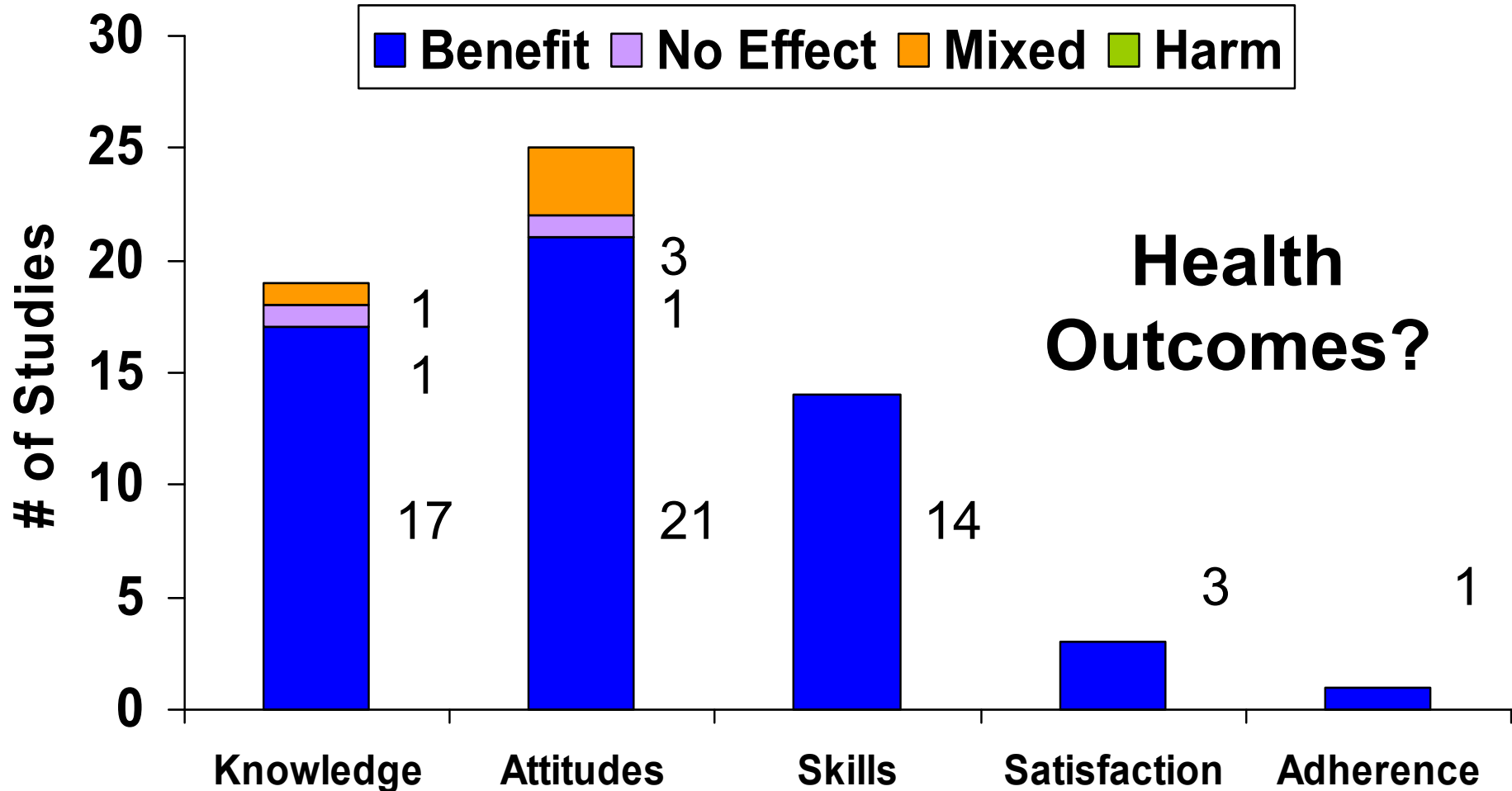


Sehgal AR. Impact of quality improvement efforts on race and sex disparities in hemodialysis. JAMA. 2003 Feb 26;289(8):996-1000.

Cultural Competence

- Cultural competence: The ability to deliver **effective** medical care to people from different cultures.
 - Culturally competent physicians are able to provide **patient-centered care** by adjusting their attitudes and behaviors to account for the impact of emotional, cultural, social and psychological issues of patients
 - Involves awareness and acceptance of cultural differences; self-awareness; knowledge of patient's culture; and adaptation of skills
 - By understanding, valuing and incorporating cultural differences of America's diverse population and examining one's own health-related values and beliefs, health providers deliver more effective and cost-efficient care.

Effectiveness of Cultural Competence Training in 34 Studies



Beach MC, Cooper LA, Robinson KA, Price EG, Gary TL, Jenckes MW, Gozu A, Smarth C, Palacio A, Feuerstein CJ, Bass EB, Powe NR. *Strategies for Improving Minority Healthcare Quality*. Agency for Healthcare Research and Quality. Rockville, MD January 2004. also Med Care. 2005 3:356-73

Let's Get Serious!

- Hold government accountable to fund research on disparities that leads to discovery of solutions

Powe NR. Let's get serious about racial and ethnic disparities. *Journal of the American Society of Nephrology* 2008 (in press)

Examining The Health Disparities Research Plan of The National Institutes of Health:

Unfinished Business

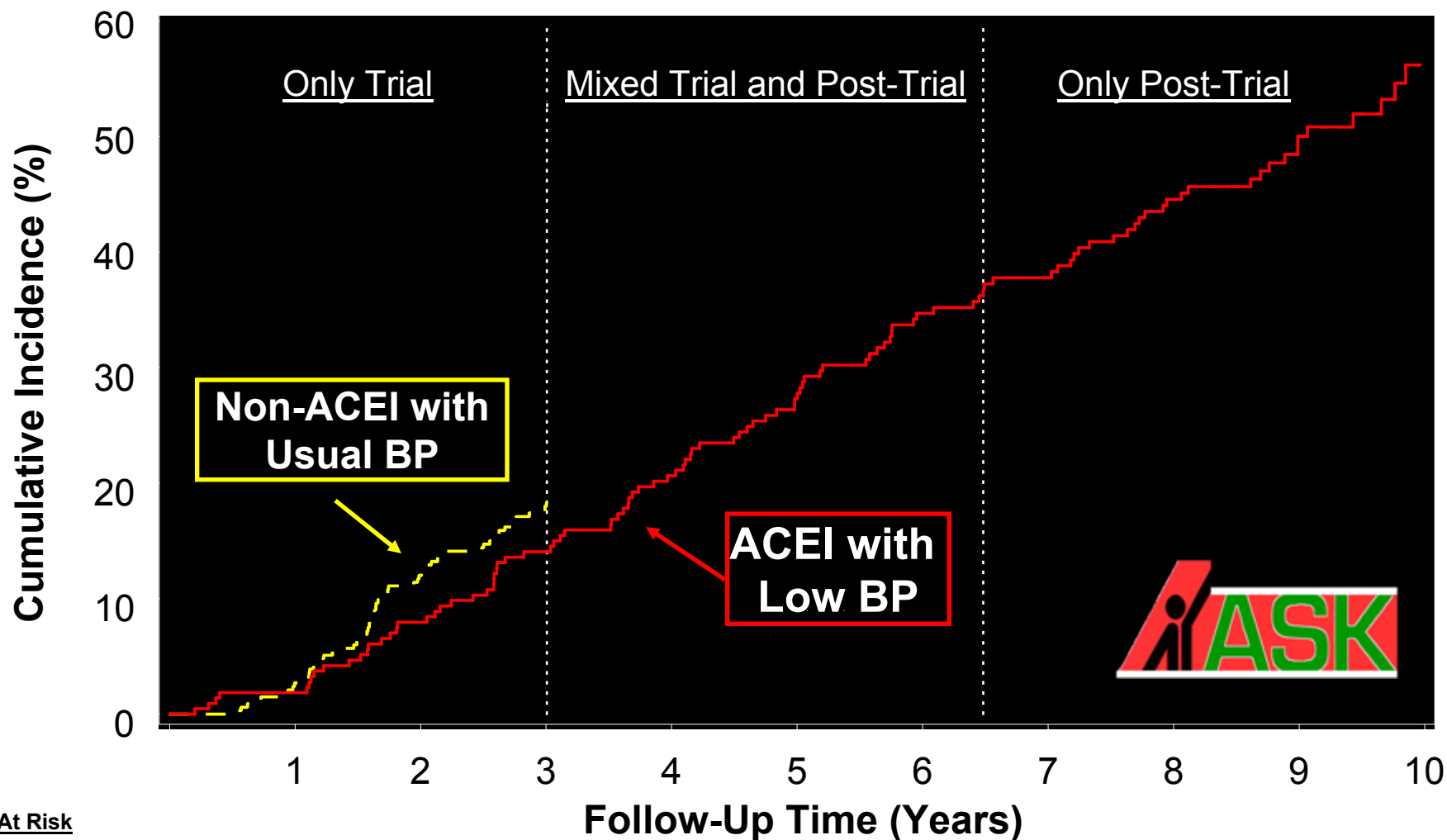
- NIH response to Minority Health and Health Disparities Research and Education Act of 2000 (P.L. 106-525) assessed by IOM ([Thomson et al](#))
- NIH ranks health disparities **third** among its top five organizational priorities,
- NIH can play a role in disparities solutions through research grants, training grants, participation in clinical trials, capacity building, study sections
- **Progress has been limited**
- **IOM Recommendations**
 - Annual strategic plan review with **measurable targets & time periods**
 - Continuous, effective coordination of the health disparities research program across the NIH
 - **Continued research on causes and solutions**



Examining the
**HEALTH DISPARITIES
RESEARCH PLAN** of the
NATIONAL INSTITUTES OF HEALTH

Unfinished Business

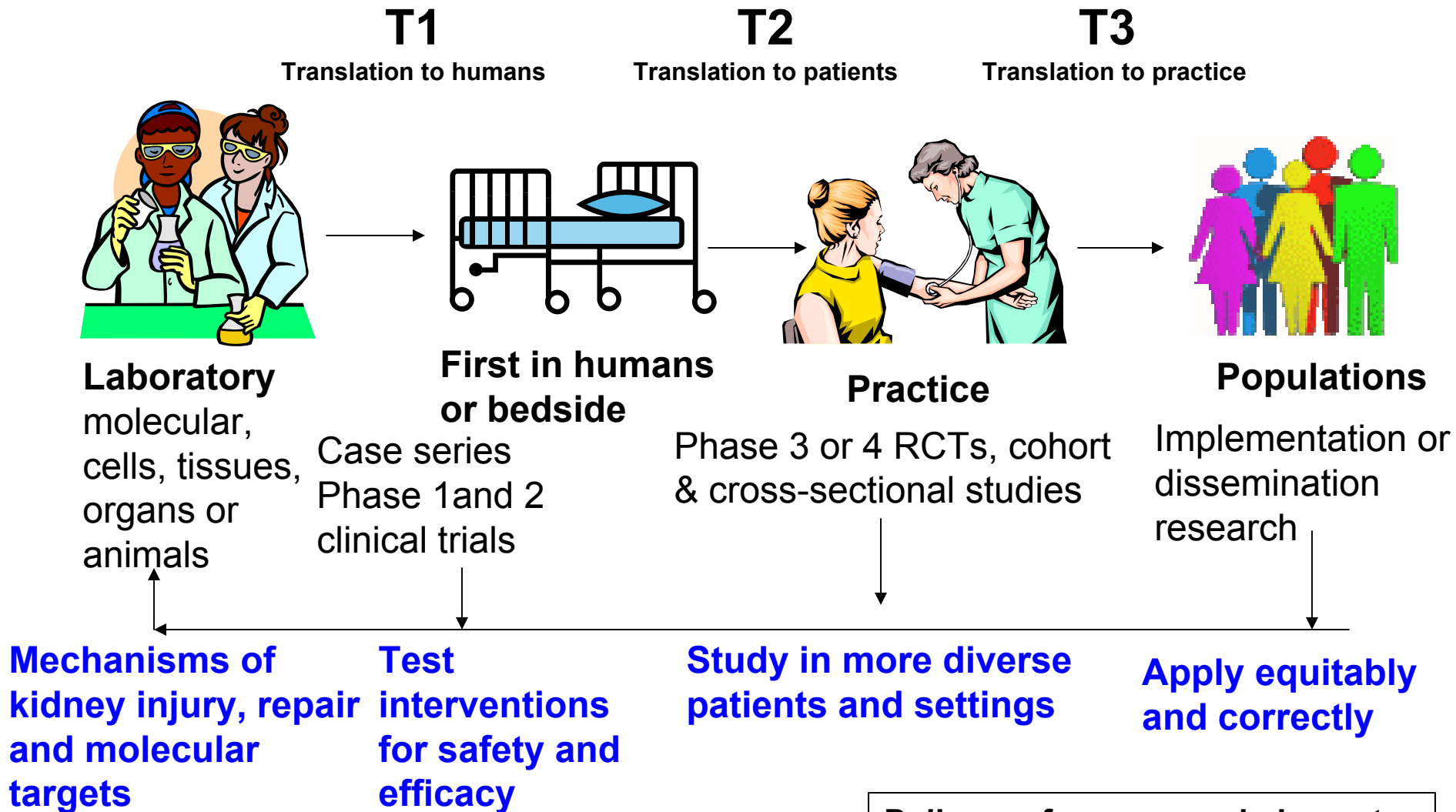
Cumulative Incidence of Events (Doubling SCr, ESRD, or Death) in African American Study of Kidney Disease (Appel et al. *Arch Intern Med* 2008 168:832-839)



Number At Risk

	1	2	3	4	5	6	7	8	9	10
Usual BP & non-ACEI:	324	293	273							
Low BP and ACEI:	215	210	183	168	151	130	120	104	63	23

Innovation is Needed to Reduce Disparities & Improve Health



Modified from Westfall JAMA. 2007;297:403-406.

Delivery of recommended care to the right person at the right time

Let's Get Serious!

- Hold government accountable to fund research that leads to discovery of solutions
- Hold ourselves and our institutions accountable for healthcare we provide
 - Make “equitable care” a performance measure
- Hold policymakers accountable for policies that promote inequitable care

Powe NR. Let's get serious about racial and ethnic disparities. *Journal of the American Society of Nephrology* 2008 (in press)

Summary

- Health disparities are the “bleeding edge of the leading edge” of Medicine
- Understanding why some race/ethnic/SES groups get a disease is fundamental:
 - Genetics and biology can inspire discoveries of new therapies through biomedical innovation
 - Role of environment/health care in disease for vulnerable groups can inform care interventions
 - Develop pre-emptive strategies for disease and its complications

Summary

- Examining race and socioeconomic disparities improves understanding of what can happen in the suboptimal circumstances
 - Inform efforts to defragment care (worse because of disruptions in family life, community and insurance)
 - Motivate us to deliver evidence-based medical care to build resiliency to future health threats
 - Inspire best ways to deliver and teach personalized, culturally competent and patient centered care
 - Inspire innovations for improved clinical performance and efficiency under resource constraints

Summary

- Activating and empowering patients with despair is a challenge
 - But tools are also widely applicable to those with resources who do not exhibit preventive behaviors (e.g. patient coaches/navigators for diabetes care)
- Diverse patients can help prepare young physicians for a more diverse U.S population and global economy
 - engage advocacy for more rough justice in the health care system

Conclusion

Science on disparities,
clinical care with diverse patients, and
education about disparities enhances
all of Medicine & human health.

Thank you