ARIC Manuscript Proposal #2681

PC Reviewed: 12/8/15	**Status: A**	**Priority: 2**
SC Reviewed: _____	**Status: _____**	**Priority: ____**

1.a. Full Title: Factors related to differences in retention among African American and white participants in the Atherosclerotic Risk in Communities Study (ARIC) prospective cohort: 1987-2013

b. Abbreviated Title (Length 26 characters): Retention differences in ARIC

2. Writing Group: Kristen M. George, Aaron Folsom, Tom Mosley, Gerardo Heiss, Anna Kucharska-Newton, Natalia Petruski-Ivleva

I, the first author, confirm that all the coauthors have given their approval for this manuscript proposal. KMG **[please confirm with your initials electronically or in writing]**

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ARIC author to be contacted if there are questions about the manuscript and the first author does not respond or cannot be located (this must be an ARIC investigator).

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3. Timeline: Finish in winter 2016, when 2013 morality data are available.

4. Rationale:

In recent decades, a concerted effort has been made to include diverse groups in clinical research. These efforts are important in order to fully understand the disease processes and causes of persistent health disparities among historically underrepresented

groups, particularly African Americans (Hieat, 2002). Unfortunately, many existing studies examining how to encourage minority participation in research only address recruitment strategies and not retention. A meta-analysis of 95 reports analyzing recruitment and retention of racial/ethnic minorities in clinical research found only 13% involved longitudinal or multi-wave studies (Yancey, 2006). The majority of reports were clinical trials or prevention trials with relatively short follow-up periods (Yancey, 2006).

The Atherosclerotic Risk in Communities Study (ARIC) provides an opportunity to examine and report the retention of African American study participants over a 27 year follow-up period and identify some factors associated with retention of this group. We will compare African American participants, as well as Jackson and Forsyth subgroups of the African American cohort, to Whites. Although the construct of race in health, which is certainly not primarily biologic, has been debated, we believe social and cultural aspects of race taken together with clinical measures will help illuminate factors that go into potentially differential attrition rates among African Americans and Whites.

References:

Heiat A, Gross CP, Krumholz HM. Representation of the elderly, women, and minorities in heart failure clinical trials. *Arch Intern Med.* 2002; 162(15).

Yancey AK, Ortega AN, and Kumanyika SK. Effective recruitment and retention of minority research participants. *Annu Review of Public Health*. 2006; 27: 1-28.

5. Main Hypothesis/Study Questions:

We hypothesize that African Americans will die, be lost to follow-up, or refuse to participate in the ARIC study at higher rates than whites over the 27 year follow-up, and there will be differences in CVD, self-reported health, and socioeconomic (SES) risk factors between races that may be associated with differential attrition rates. We also believe there will be race-specific differences in CVD risk factors between study participants who have remained active ARIC participants, participants who have died, and participants who were lost to follow-up or withdrew from the study.

The proposed study overlaps significantly with ARIC MS#2382 "Examining the Healthy Cohort Effect: Predictors of Attrition in the Atherosclerosis Risk in Communities (ARIC) Study", of which Dr. Anna Kucharska-Newton is now the lead author. We have discussed the overlap with Dr. Kucharska-Newton and agree that by specifically focusing the present proposal on the association of race with attrition we will be examining only one of the factors that may lead to non-participation. Dr. Kucharska-Newton is also a member of the writing group for the present manuscript proposal.

6. Design and analysis (study design, inclusion/exclusion, outcome and other variables of interest with specific reference to the time of their collection, summary of data analysis, and any anticipated methodologic limitations or challenges if present).

For the analyses, we will exclude non-white and non-African American participants, leaving 15,689 individuals whose censoring status was tracked from baseline, 1987-89, through visit 5, 2011-13**.** We will use available censoring data to create three participation categories, 'remained active,' 'lost or withdrew,' and 'died,' by visit 5 for analysis.

Our first aim is to illustrate the retention rates of ARIC participants from baseline visit 1, 1987-89, through visit 5, 2011-13, stratified by race. Race and center specific life-tables will be created, showing, over time, the proportions of participants who (i) died, (ii) were lost or withdrew from continued contact, or (iii) remained active (i.e., continued study phone calls) through 2013. Our second aim is to describe retention in relation to baseline characteristics or certain characteristics after baseline (incident CVD, self-reported health, and SES). We will describe race and center specific prevalences or means and standard deviations for risk factors formerly mentioned. Our third aim is to determine how attrition between 1987 and 2013 affected the previously reported risk factor differences between African Americans and whites. We will evaluate prevalences for visit 5 risk factors, stratified by race, among those who attended the visit 5.

7.a. Will the data be used for non-CVD analysis in this manuscript? ____ Yes __X__ No

b. If Yes, is the author aware that the file ICTDER03 must be used to exclude persons with a value RES_OTH = "CVD Research" for non-DNA analysis, and

for DNA analysis RES_DNA = "CVD Research" would be used? ____ Yes ____ No
(This file ICTDER has been distributed to ARIC PIs, and contains the responses to consent updates related to stored sample use for research.)

8.a. Will the DNA data be used in this manuscript?
____ Yes __X__ No

8.b. If yes, is the author aware that either DNA data distributed by the Coordinating Center must be used, or the file ICTDER03 must be used to exclude those with value RES_DNA = "No use/storage DNA"?
____ Yes ____ No

9. The lead author of this manuscript proposal has reviewed the list of existing ARIC Study manuscript proposals and has found no overlap between this proposal and previously approved manuscript proposals either published or still in active status. ARIC Investigators have access to the publications lists under the Study Members Area of the web site at: http://www.cscc.unc.edu/ARIC/search.php

___**X** ___ Yes _____ No

10. What are the most related manuscript proposals in ARIC (authors are encouraged to contact lead authors of these proposals for comments on the new proposal or collaboration)?

Jackson R, Chambless LE, Yang K, et al. Differences between respondents and nonrespondents in a multicenter community-based study vary by gender and ethnicity. *J Clin Epidemiol*. 1996; 49(12): 1441-1446.

MS 2382

11.a. Is this manuscript proposal associated with any ARIC ancillary studies or use any ancillary study data? ____ Yes __X__ No

11.b. If yes, is the proposal
___ A. primarily the result of an ancillary study (list number* _____)
___ B. primarily based on ARIC data with ancillary data playing a minor role (usually control variables; list number(s)* _____ _____ _____)

*ancillary studies are listed by number at http://www.cscc.unc.edu/aric/forms/

12a. Manuscript preparation is expected to be completed in one to three years. If a manuscript is not submitted for ARIC review at the end of the 3-years from the date of the approval, the manuscript proposal will expire.

12b. The NIH instituted a Public Access Policy in April, 2008 which ensures that the public has access to the published results of NIH funded research. It is **your responsibility to upload manuscripts to PUBMED Central** whenever the journal does not and be in compliance with this policy. Four files about the public access policy from http://publicaccess.nih.gov/ are posted in http://www.cscc.unc.edu/aric/index.php, under Publications, Policies & Forms. http://publicaccess.nih.gov/submit_process_journals.htm shows you which journals automatically upload articles to PubMed central.

13. Per Data Use Agreement Addendum for the Use of Linked ARIC CMS Data, approved manuscripts using linked ARIC CMS data shall be submitted by the Coordinating Center to CMS for informational purposes prior to publication. Approved manuscripts should be sent to Pingping Wu at CC, at pingping_wu@unc.edu. I will be using CMS data in my manuscript ____ Yes __**X**__ No.