Contents lists available at ScienceDirect





**Contemporary Clinical Trials Communications** 

journal homepage: www.elsevier.com/locate/conctc

# Where are they now? Retention strategies over 25 years in the Coronary Artery Risk Development in Young Adults (CARDIA) Study



Ellen Funkhouser<sup>a,\*</sup>, Jennifer Wammack<sup>a</sup>, Cathy Roche<sup>b</sup>, Jared Reis<sup>c</sup>, Stephen Sidney<sup>d</sup>, Pamela Schreiner<sup>e</sup>

<sup>a</sup> Division of Preventive Medicine, Department of Medicine, School of Medicine, University of Alabama at Birmingham, 3201 1st Avenue North, Birmingham, AL, 35222-4410, United States

<sup>b</sup> Department of Nursing Family & Community Health, School of Nursing, University of Alabama at Birmingham, 3201 1st Avenue North, Birmingham, AL, 35222-1210, United States

<sup>c</sup> Division of Cardiovascular Sciences, National Heart, Lung, and Blood Institute, Bethesda, MD, 20892, United States

<sup>d</sup> Division of Research, Kaiser Permanente Northern California, Oakland, CA, 94612, United States

<sup>e</sup> Division of Epidemiology & Community Health, University of Minnesota, Minneapolis, MN, 55454, United States

## ARTICLE INFO

Keywords: Retention rates Retention strategies Longitudinal studies Cohort studies

# ABSTRACT

*Purpose*: In 1991, we described the recruitment and goals for a cohort of young adults. At the time, little was known about long-term retention of young, healthy and mobile adults or minorities. We present retention strategies and rates over 25 years, and predictors of participation at the year 25 follow-up examination of the Coronary Artery Risk Development in Young Adults (CARDIA) Study, a longitudinal investigation of coronary artery disease risk factors in a biracial population initially ages 18–30 years recruited from four U.S. centers in 1985.

*Methods*: CARDIA has employed a range of strategies to enhance retention, including two contacts per year, multiple tracking methods to locate participants lost-to-follow-up, use of birthday and holiday cards, participant newsletters, examination scheduling accommodations and monetary reimbursements, and a standing committee whose primary purpose has been to continually review retention rates and strategies and identify problems and successes.

*Results:* For 25 years, CARDIA has maintained > 90% contact with participants between examinations, over 80% at any 2-year interval, and a 72% 25-year examination attendance rate. Baseline predictors of year 25 examination attendance include white race, female sex, older age, higher education, nonsmoking and moderate alcohol consumption.

*Conclusion:* Consistent use of multiple retention strategies, including attention to contact rates and sharing of best strategies across study centers, has resulted in high retention of a diverse, initially young, biracial cohort.

#### 1. Introduction

In 1991, we described the recruitment and goals for a cohort of black and white young adults with variable educational attainment [1]. At the time, little was known about long-term retention of young, healthy and mobile adults or minorities. Twenty-five years later, we describe recruitment and retention strategies for this population-based biracial cohort of young adults, initially ages 18–30 years in 1985–86, recruited from four geographic locations [9,10]. Participant retention in long-term longitudinal studies is critical for both internal and external validity. A number of factors have been positively associated

with study retention, including white race [2–4], female sex [3,4] and higher level of educational attainment [2,3,5], while smoking [2,4], obesity [4,6], and moderate-severe depression levels [5] have been associated with lower participant retention.

Two recent systematic reviews have examined retention strategies and their effects on retention [7,8]. Most of the studies reviewed were randomized trials of less than two years' duration. In general, the more retention strategies employed, the better the retention, with incentives, both monetary and nonmonetary, improving retention; reminder calls and letters were also consistently found to improve retention, but to a lesser degree. Booker et al. [8] noted that retention strategies for

<sup>\*</sup> Corresponding author.

https://doi.org/10.1016/j.conctc.2017.12.003

Received 23 March 2017; Received in revised form 16 December 2017; Accepted 19 December 2017 Available online 20 December 2017

2451-8654/ © 2017 Published by Elsevier Inc. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/BY-NC-ND/4.0/).

E-mail addresses: emfunk@uab.edu (E. Funkhouser), jwammack@uab.edu (J. Wammack), croche@uab.edu (C. Roche), reisjp@nhlbi.nih.gov (J. Reis), steve.sidney@kp.org (S. Sidney), schre012@umn.edu (P. Schreiner).

Abbreviations and acronyms		
CARDIA	Coronary Artery Risk Development in Young Adults	
CC&RS	Clinic Coordination and Retention Subcommittee	
Y25	year 25	
Y20	year 20	

longitudinal studies may be different from shorter term clinical trials due to long-term commitment.

Observational studies of chronic diseases require long follow-up, but systematic evaluations of retention strategies in these studies are lacking. Participants in closed cohorts after a baseline recruitment period are irreplaceable. Studying methods currently used in existing cohorts, as well as characteristics of these populations and the accompanying retention rates, is a logical strategy to understand retention success, but has not been done for middle-aged participants.

The Coronary Artery Risk Development in Young Adults (CARDIA) Study is a longitudinal investigation of coronary artery disease risk factors in black and white men and women that has followed participants for over 25 years. To date, CARDIA has completed eight examination cycles: a baseline examination during 1985–1986 (n = 5115) and follow-up examinations at 2, 5, 7, 10, 15, 20 and 25 years after baseline. The CARDIA Study recruitment was designed to be balanced across eight strata: race (black/white), sex (men/women), age (18–24/25-30 years) and educational attainment (high school education or less/more than high school) in four distinct geographic locations (Birmingham, AL; Chicago, IL; Minneapolis, MN; Oakland, CA).

This cohort provides a unique opportunity to describe retention strategies from young adulthood through middle age, as well as predictors of long-term retention over 25 years.

#### 2. Methods

### 2.1. Overall retention strategies

Since the CARDIA Study began in 1985, the study protocol for participant retention has included the following: 1) obtaining information on three designated contacts for each participant at a midyear and annual contact; 2) producing bimonthly standardized contact reports reviewed by the study investigators; and 3) creating a Clinic Coordination and Retention Subcommittee (CC&RS) to facilitate retention. Retention methods used were approved by the Institutional Review Board of each field center and the Coordinating Center. Information on three designated contacts was obtained from participants at the time of initial enrollment, including name, relation to participant, mailing address and telephone numbers. Follow-up contacts are made every six months to verify each participant's contact information and vital status, and to update designated contact information. In later years, this information has also included email addresses, if available. Either the participant or a proxy can provide information for this mid-year contact. At annual follow-up contacts, each participant's health and hospitalization status are also obtained. The Coordinating Center posts standardized contact reports bimonthly on a secure internal website for field center coordinators and study investigators to review; the CC&RS meets monthly to identify both problems and successful methods. Because staff and retention techniques vary by field center, the CC&RS members also exchange successful local retention strategies.

Across field centers, specific methods of contact have varied between using the U.S. Postal Service as the initial contact mode, followed by telephone contact for those not returning forms, and telephone contact for both initial and reminder contact. Although not explicitly part of the study protocol, all field centers send birthday and holiday cards to participants as another retention strategy; family members are Contemporary Clinical Trials Communications 9 (2018) 64-70

Y2	year 2
U.S.	United States
BMI	Body mass index
ARIC	Atherosclerosis Risk in Communities
CHS	Cardiovascular Health Study

sent condolence cards in the event of a participant death.

#### 2.2. Year 25 examination retention activities

Retention strategies have been comparable across clinics for all examinations, with some variation in implementation. We will focus on the year 25 (Y25) examination, when the participants were ages 43–55 years.

*Participant satisfaction questionnaire.* To help inform investigators during planning for the Y25 examination, a brief questionnaire was added to the mid-year follow-up contact preceding the examination to solicit participant opinions (Appendix A). Early on, CARDIA investigators obtained responses to study satisfaction questions in order to give participants a voice in planning for future follow-up examinations. The satisfaction questionnaire provides a pathway for enhanced collaboration between investigators and participants.

*Participant newsletters*. Annual study-wide participant newsletters highlight clinical results from examinations, inform participants of upcoming examinations and the components, introduce participants to center-specific staff or news, and to share select scientific publications. Prior to the Y25 examinations, participants were also mailed a refrigerator magnet with the examination dates and all relevant field center contact information.

*Toll-free number*. Each field center maintains a toll-free number as a convenience for out-of-town participants to contact either their baseline examination clinic or examining clinic (if different from baseline clinic) as well as a general email address.

*Travel accommodations.* Each field center offers transportation assistance at no cost to participants for local clinic visits. CARDIA is distinctive for offering reimbursement for travel expenses to out-of-town participants who have relocated outside the immediate area of their home clinic. This can include airfare, hotel accommodations and/ or mileage reimbursement. Participants can choose to return to their home clinic or to be examined at the field center closest to their current residence. Clinic staff often tries to coordinate a clinic visit with a planned visit to the area for other purposes, which not only assures the participant will be in the area, but also provides a positive incentive by helping him or her with the cost of travel plans.

*Scheduling accommodations.* Each field center offers alternate appointment options for participants with time constraints, including completing their examination over multiple days and alternate appointment times, such as later in the morning or an afternoon clinic. Abbreviated exams (see Appendix B for details), ranked by research priorities, are offered to participants with limited time and who would not otherwise attend the examination.

Reimbursement and 'thank you' gifts. Each field center offers study non-monetary gifts, such as t-shirts, for participation and monetary reimbursement for participant time and expenses. Monetary reimbursement of up to \$60 for the core examination was also provided to each participant who attended the Y25 examination to cover parking, child care, missed work, or other expenses; the timing and form of payment varied across sites. The Birmingham clinic provided a *Visa CheckCard* for the full amount at the conclusion of each participant's examination visit, while the Chicago clinic provided \$40 in cash at the conclusion of each participant's examination visit and subsequently mailed him/her a \$20 check; the Minneapolis and Oakland clinics both provided a check for the full amount. Reimbursement for ancillary Download English Version:

# https://daneshyari.com/en/article/8519329

Download Persian Version:

https://daneshyari.com/article/8519329

Daneshyari.com