# **Racial Differences in Enrolment in a Cancer Genetics Registry**

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## Abstract

Background: Lower enrolment of minorities into research studies has been reported frequently. Most studies have little information about nonparticipants, making it difficult to identify characteristics associated with enrolment and how they might vary by race. Methods: Women who had previously participated in a population-based, case-control study of breast cancer in North Carolina were invited to enrol in a cancer genetics registry. Detailed questionnaire data on sociodemographic characteristics and cancer risk factors were available for all women. We compared characteristics of women who agreed to be in the registry with those who were deceased, were unlocatable, or declined enrolment. Unconditional logistic regression analyses were done to identify predictors of enrolment. Results: Enrolment rates were markedly lower among African Americans than Whites (15% and 36%, respec-

### Introduction

Concerns about minority enrolment in research studies have been discussed extensively in the scientific literature. Lower participation rates among minorities, particularly African Americans, have been reported frequently (1-4). Several factors may contribute to the apparent reluctance of African Americans to join research studies, including mistrust of the medical and research establishment because of historical abuses such as the Tuskegee study, lack of understanding about research, concerns about the relevancy of research, and socioeconomic factors (5-10). Strategies employed to increase African Americans' participation rates include matching potential participants and interviewers on race, using minority-targeted outreach programs, developing research orientation programs, and tailoring enrolment procedures to overcome literacy barriers (1, 3). Although these approaches have improved response rates in some cases, minority participation still tends to lag behind that of Whites.

A prime difficulty in trying to understand reasons for lower participation rates among minorities is typically

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tively) due to both lower contact rates (41% versus 63%) and lower enrolment rates among those contacted (37% versus 58%). Logistic regression models suggested that racial differences in enrolment were not due to socioeconomic characteristics or other cancer risk factors; race was the only significant predictor of enrolment in multivariable models (odds ratio 0.41, 95% confidence interval 0.23-0.72). Conclusions: Although all women had previously taken part in a research study, African American women were less likely to enrol in the cancer genetics registry than White women. A possible explanation of these findings is that studies of genetics may present particular concerns for African Americans. Further research is needed to identify attitudes and issues that present barriers to participation among minorities. (Cancer Epidemiol Biomarkers Prev 2004;13(8):1349-54)

there is little information available on characteristics of individuals who decline to take part in research other than basic demographic descriptors such as age and race. Although investigators sometimes ask about reasons for not participating, most subjects either refuse to answer or provide vague answers such as "not interested" or "too busy" (11). We had an opportunity within the Carolina-Georgia Center of the Cancer Genetics Network (CGN) to more fully explore differences in sociodemographic characteristics and cancer risk factors between women who enrolled in the CGN registry and those who declined.

The CGN is a multicenter collaboration in which individuals with a personal or family history of cancer are enrolled into a registry. Women who had previously taken part in the Carolina Breast Cancer Study (CBCS) and who met CGN eligibility criteria were invited to join the registry. All invited women from the CBCS had completed a comprehensive questionnaire on breast cancer risk factors. Thus, they were acquainted with and apparently receptive to being involved in research. Nonetheless, many CBCS participants declined to enrol in the CGN registry. The availability of questionnaire information from CBCS participants allowed us to examine characteristics associated with enrolment and whether these characteristics varied by race. In this report, we describe enrolment rates in the Carolina-Georgia CGN among African American and White women and characteristics of participants and nonparticipants.

#### **Materials and Methods**

The CGN is a network of eight centers funded by the National Cancer Institute to support collaborative research on genetic determinants of cancer risk partly through the establishment of a registry of individuals with a personal or family history of cancer who would be interested in participating in studies of genetics and cancer (12). Individuals are recruited into the registry through physician referrals, brochures in doctors' offices, a Web site, and invitations to participants in other research studies. Enrolled individuals complete a questionnaire on family history and cancer risk factors and are recontacted annually to update information. Registry participants are informed that they may be contacted for future studies of cancer and genetics but are under no obligation to participate in these studies.

The Carolina-Georgia CGN center invited breast cancer cases who had previously taken part in the CBCS and who met specific eligibility criteria to enrol in the CGN. The CBCS was a population-based, case-control study conducted in North Carolina between 1993 and 2000; its goal was to identify genetic and environmental etiologic factors for breast cancer within a population that was predominantly White and African American (13). African American women who were oversampled comprised  $\sim 40\%$  of the CBCS study population. Among eligible cases, 97% were contacted and 77% agreed to enrol in the CBCS (1). All women completed an interviewer-administered questionnaire on cancer risk factors, had body measurements taken, and gave a blood sample. As part of the informed consent procedures, participants were told that their blood samples might be used to study genes involved in breast cancer including BRCA1 and BRCA2.

CBCS participants were invited to enrol in the CGN if they had personal or family histories of breast, colon, ovarian, or prostate cancer diagnosed at a young age (<45 to <55 years depending on site) and/or multiple relatives who had cancers suggestive of a hereditary syndrome (e.g.,  $\geq 2$  relatives with the same type of cancer,  $\geq 2$  relatives with related cancers, such as endometrial and colon, etc.).

A CBCS staff member sent a letter to each eligible woman requesting permission to forward her contact information to CGN study staff. A response form and postage-paid envelope were included with the letter in which the respondents were asked to indicate whether it would be acceptable to give their contact information to the CGN or if they wanted more information before deciding. If no response was received, CBCS study staff attempted to reach the woman by telephone, calling up to six times at various times of day or days of the week. If letters were undeliverable, various strategies were used to identify updated addresses including Internet searches. Deaths were confirmed by family members or by the Social Security Death Index. The study protocol was approved by the institutional review board at the University of North Carolina (Chapel Hill, NC).

Enrolment in the CGN reflects two levels of contact and response. Because some women had taken part in the CBCS >5 years before the CGN began recruitment, many could not be contacted either because they were deceased or had moved. Among those who could be contacted, women fell into three categories:

- (1) declined to receive CGN information,
- (2) received information then declined to participate, and
- (3) agreed to participate.

We first compared characteristics of women by categories of response stratified by race using  $\chi^2$  tests and ANOVA. Then, among contacted women, we used unconditional logistic regression modeling to evaluate factors that predicted enrolment and determine whether race remained an independent predictor of enrolment when controlling for socioeconomic characteristics and other factors.

#### Results

Analyses were based on 872 CBCS participants who described their race as White or African American, met CGN eligibility criteria, and were invited to enrol in the CGN. We excluded 14 women whose reported race was neither White nor African American. Table 1 presents results of attempts to invite women into the CGN. Overall, the proportion of women who enrolled was much smaller for African Americans than for Whites (15% versus 36%). Lower enrolment among African American women resulted from both a lower contact rate and a higher refusal rate among those contacted. We achieved contact with significantly fewer African Americans than Whites (41% and 63%, respectively, P <0.0001), reflecting higher percentages of both deceased and unlocatable women. Among those contacted, African Americans were significantly less likely than Whites to enrol in the CGN registry (37% versus 58%, P < 0.0001). Although the proportion of women who declined to receive CGN materials did not differ markedly between races, a greater proportion of African American women declined to participate after receiving CGN materials.

Table 2 presents descriptive characteristics within each race stratifying by response category. The most striking difference in characteristics by category of response was

Table 1. Distribution of CBCS participants invited toenrol in the CGN registry by race, North Carolina, 1999to 2001

	Whites, n (%)	African Americans, n (%)	Р
Results of contact attempts			
Contacted	322 (63)	147 (41)	< 0.0001
Not contacted, deceased	56 (11)	63 (18)	
Not contacted, unlocatable	135 (26)	149 (42)	
Total	513 (100)	359 (100)	
Enrolment decisions among	g contacted wo	omen	
Enrolled in CGN	186 (58)	54 (37)	< 0.0001
Received CGN materials then declined	89 (28)́	67 (46)́	
Declined to receive CGN materials	47 (15)	26 (18)	
Total	322 (100)	147 (100)	
Overall enrolment rates	186/513 (36)	54/359 (15)	< 0.0001

	Joined CGN	Received CGN materials then declined	Declined to receive CGN materials	Deceased	Unlocatable	Р
Whites						
<i>n</i> Age at interview (y), mean (SD) Years since CBCS interview, mean (SD) No. of pregnancies, mean (SD) Age at first birth (y), mean (SD) Age at menarche (y), mean (SD) Body mass index (kg/m <sup>2</sup> ), mean (SD) Waist-to-hip ratio, mean (SD)	186 44.6 (9.7) 4.3 (2.2) 2.3 (1.5) 26.3 (5.1) 12.6 (1.5) 25.2 (5.8) 0.78 (0.07)	89 46.3 (11.8) 4.4 (2.0) 2.2 (1.6) 24.2 (5.7) 12.6 (1.5) 25.8 (5.7) 0.78 (0.07)	$\begin{array}{c} 47\\ 50.6\ (12.9)\\ 5.2\ (2.0)\\ 2.3\ (1.4)\\ 24.2\ (4.6)\\ 12.7\ (1.3)\\ 24.4\ (4.7)\\ 0.80\ (0.07) \end{array}$	56 42.8 (8.4) 5.3 (1.8) 2.7 (2.6) 23.0 (4.9) 12.1 (1.5) 26.5 (5.6) 0.80 (0.07)	135 43.7 (11.4) 5.7 (2.0) 2.2 (1.8) 23.8 (5.2) 12.4 (1.5) 25.2 (5.4) 0.78 (0.08)	$\begin{array}{c} 0.001 \\ < 0.0001 \\ 0.33 \\ < 0.0001 \\ 0.27 \\ 0.33 \\ 0.26 \end{array}$
Stage at diagnosis, <i>n</i> (%) Stage 0 or I Stage II or higher Missing	116 (64) 65 (36) 5	55 (66) 28 (34) 6	31 (67) 15 (33) 1	6 (12) 43 (88) 7	74 (58) 54 (42) 7	<0.0001
Educational level, <i>n</i> (%) Less than high school High school graduate College graduate Missing	9 (5) 86 (46) 91 (49) 0	5 (6) 58 (65) 26 (29) 0	4 (9) 26 (55) 17 (36) 0	5 (9) 35 (63) 16 (29) 0	11 (8) 76 (56) 48 (36) 0	0.007
Family income (\$), <i>n</i> (%) <20,000 20,000-50,000 >50,000 Missing	18 (10) 59 (32) 105 (58) 4	11 (14) 25 (31) 45 (56) 8	7 (17) 18 (44) 16 (39) 6	9 (19) 24 (47) 18 (35) 5	23 (18) 66 (52) 37 (29) 9	0.001
Farmer, service worker Craftworker, clerical Professional, administrator Never worked	6 (3) 77 (41) 103 (55) 0	8 (9) 43 (48) 37 (42) 1	3 (6) 27 (57) 16 (34) 1	7 (13) 30 (54) 19 (34) 0	14 (10) 67 (50) 52 (39) 0	0.01
Breast or ovarian cancer in mother or sister, $n$ (%) Current physical activity, $n$ (%) Current smoker, $n$ (%)	62 (33) 110 (59) 20 (11)	23 (26) 51 (57) 21 (24) 72 (21)	17 (36) 30 (64) 7 (15) 21 (66)	12 (21) 29 (52) 14 (25) 28 (68)	67 (50) 31 (23)	0.14 0.33 0.12
	138 (85)	72 (01)	51 (00)	38 (08)	104 (77)	0.01
African Americans n Age at interview (y), mean (SD) Years since CBCS interview, mean (SD) No. of pregnancies, mean (SD) Age at first birth (y), mean (SD) Age at menarche (y), mean (SD) Body mass index (kg/m <sup>2</sup> ), mean (SD) Waist-to-hip ratio, mean (SD) Stage at diagnosis $n$ (%)	54 43.4 (8.9) 4.1 (2.2) 2.9 (2.0) 22.0 (5.5) 12.4 (1.5) 30.6 (7.2) 0.83 (0.07)	67 48.4 (12.6) 4.1 (2.0) 3.6 (2.6) 21.9 (6.6) 12.6 (1.6) 32.8 (9.1) 0.84 (0.08)	26 50.3 (12.3) 4.1 (1.9) 2.5 (1.5) 22.6 (5.0) 12.4 (1.6) 33.6 (7.1) 0.83 (0.06)	63 43.8 (11.1) 5.2 (2.2) 3.2 (2.4) 20.2 (4.6) 12.5 (1.6) 32.4 (8.1) 0.86 (0.09)	149 44.1 (11.7) 4.8 (2.2) 3.4 (2.6) 20.4 (4.5) 12.5 (1.8) 32.1 (8.5) 0.84 (0.07)	$\begin{array}{c} 0.008\\ 0.05\\ 0.21\\ 0.07\\ 0.94\\ 0.55\\ 0.35\end{array}$
Stage 0 or I Stage II or higher Missing	22 (43) 29 (57) 3	30 (47) 34 (53) 3	10 (40) 15 (60) 1	9 (15) 51 (85) 3	50 (36) 88 (64) 11	0.003
Educational level, <i>n</i> (%) Less than high school High school graduate College graduate Missing Eamily income (\$) <i>n</i> (%)	8 (15) 33 (62) 12 (23) 1	17 (25) 39 (58) 11 (16) 0	2 (8) 21 (81) 3 (12) 0	18 (29) 31 (49) 14 (22) 0	39 (26) 83 (56) 27 (18) 0	0.68
<pre>&lt;20,000 20,000-50,000 &gt;50,000 Missing Usual occupation category # (%)</pre>	16 (32) 27 (54) 7 (14) 4	33 (52) 21 (33) 10 (16) 3	17 (65) 7 (27) 2 (8) 0	29 (49) 23 (39) 7 (12) 4	76 (54) 54 (38) 11 (8) 8	0.05
Farmer, service worker Craftworker, clerical Professional, administrator Never worked	$ \begin{array}{c} 11 (21) \\ 28 (53) \\ 14 (26) \\ 1 \\ 16 (20) \end{array} $	19 (28) 33 (49) 15 (22) 0 24 (26)	8 (31) 16 (62) 2 (8) 0 9 (25)	$ \begin{array}{c} 16 (25) \\ 35 (56) \\ 12 (19) \\ 0 \\ 15 (24) \end{array} $	47 (33) 72 (51) 23 (16) 7 26 (18)	0.23
The physical concerning the physical activity, $n$ (%) Current physical activity, $n$ (%) Current smoker, $n$ (%) Ever alcohol use, $n$ (%)	16 (30) 25 (46) 8 (15) 33 (61)	24 (36) 35 (52) 10 (15) 45 (67)	9 (35) 15 (58) 3 (12) 17 (65)	15 (24) 25 (40) 6 (10) 39 (62)	26 (18) 64 (43) 38 (26) 95 (64)	0.05 0.40 0.04 0.96

Table 2.	Descriptive	characteri	istics of	White	and Af	rican 🌶	American	women	invited	to jo	in the	CGN	registry	by
categori	ies of respon	se, North	Carolina	, 1999	to 2001					-				-

that a large proportion of deceased women had been diagnosed with later-stage breast cancer. Other characteristics showed less striking differences between response categories. Among both races, the data suggested that women who joined the CGN were more likely to be younger and have higher income than those who declined.

Logistic regression models were used to identify factors associated with CGN enrolment among women who were located and contacted (Table 3). Unadjusted analyses showed many factors with statistically significant associations with enrolment including younger age, White race, lower body mass index, lower waist-to-hip ratio, higher education, higher income, and higher occupational category. The multivariable model controlling for all factors simultaneously showed a strong association with race (African Americans were less than half as likely to enrol as Whites) and an inverse association of borderline significance with age. No other factors, including markers of socioeconomic status, were significant predictors of CGN enrolment. We also did race-specific logistic regression modeling to determine if different factors were associated with CGN enrolment among African American and White women. With the exception of less advanced stage at diagnosis among African American women, multivariable analyses did

not identify any factors including socioeconomic characteristics that had significant associations with CGN enrolment in either race.

### Discussion

Among previous CBCS participants, we examined factors predicting CGN enrolment. One characteristic of this analysis that distinguishes it from most other studies evaluating racial differences in participation rates is that invited women had previously taken part in research. Because they had been receptive to participating in research in the past, we presumably had already eliminated women for whom factors such as a general mistrust of research (5, 14) precluded their enrolment in any study. However, despite their prior research experience, we still found much lower enrolment rates among African Americans than Whites. Data obtained from their prior participation in the CBCS allowed us to assess several characteristics that could be associated with the decision to enrol in a study. Although we had more data on nonparticipants than are generally available to investigators, it is important to note that we had no data related to attitudes and beliefs that might influence enrolment decisions.

Table 3. Predictors of enrolment in the CGN for all, White, and African American women from unadjusted and multivariable logistic regression models, North Carolina, 1999 to 2002 odds ratio (95% confidence interval)

	All women $(n = 469)$		Whites ( <i>n</i> = 322)	African Americans $(n = 147)$	
	Unadjusted	Multivariable adjusted <sup>*</sup>	Multivariable adjusted <sup>*</sup>	Multivariable adjusted <sup>*</sup>	
Age at interview (v)	0.97 (0.95-0.98)	0.98 (0.96-1.00)	0.98 (0.95-1.01)	0.97 (0.93-1.02)	
Race (White as reference category)	0.43 (0.28-0.63)	0.41 (0.23-0.72)	_ ` `	_ ` `	
Years since CBCS interview	0.97 (0.89-1.06)	0.98 (0.89-1.09)	0.96(0.84 - 1.09)	1.11 (0.91-1.36)	
Body mass index $(kg/m^2)$	0.96 (0.94-0.99)	1.00 (0.96-1.04)	1.02 (0.96-1.07)	0.98 (0.92-1.05)	
Waist-to-hip ratio (0.1 unit)	0.74 (0.59-0.94)	1.08 (0.76-1.53)	1.00 (0.64-1.58)	1.28 (0.62-2.63)	
Age at menarche $(v)$	0.96 (0.85-1.09)	0.95 (0.82-1.10)	0.92 (0.77-1.10)	0.98 (0.74-1.31)	
Age at first birth $(y)$					
<20	0.46 (0.25-0.87)	0.71 (0.33-1.53)	0.42 (0.14-1.23)	1.06 (0.26-4.30)	
20-24	0.74 (0.42-1.32)	0.80 (0.39-1.63)	0.86 (0.37-2.00)	0.38 (0.08-1.77)	
25-29	1.09 (0.60-1.97)	0.98 (0.48-1.99)	1.09 (0.48-2.47)	0.74 (0.14-3.84)	
≥30	1.29 (0.67-2.50)	1.11 (0.51-2.40)	1.19 (0.48-2.98)	0.80 (0.15-4.30)	
Nulliparous	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	
Stage (stage 0-I vs II-IV)	1.07 (0.74-1.56)	1.09 (0.91-1.32)	0.95 (0.75-1.21)	1.44 (1.01-2.07)	
Educational level					
Less than high school	0.34 (0.17-0.67)	1.04 (0.33-3.27)	1.76 (0.34-9.32)	0.50 (0.06-4.05)	
High school graduate	0.46 (0.31-0.69)	0.63 (0.34-1.15)	0.68 (0.33-1.40)	0.72 (0.19-2.66)	
College graduate	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	
Family income (\$)	. ,	. ,	. ,	, , ,	
<20,000	0.33 (0.20-0.54)	0.78 (0.37-1.65)	1.14 (0.39-3.30)	0.64 (0.15-2.72)	
20,000-50,000	0.79 (0.51-1.22)	1.37 (0.81-2.32)	1.28 (0.70-2.36)	2.13 (0.62-7.31)	
>50,000	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	
Usual occupation category					
Farmer, service worker	0.27 (0.14-0.51)	0.56 (0.22-1.44)	0.38 (0.10-1.47)	0.94 (0.17-5.27)	
Craftworker, clerical	0.53 (0.36-0.78)	1.16 (0.62-2.16)	1.13 (0.54-2.35)	0.85 (0.21-3.40)	
Professional, administrator	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	
Family history of breast or ovarian cancer (mother/sister)	1.03 (0.70-1.52)	1.41 (0.87-2.30)	1.55 (0.84-2.85)	1.07 (0.39-2.96)	
Current physical activity	0.96 (0.67-1.39)	1.10 (0.71-1.70)	1.03 (0.59-1.80)	1.44 (0.61-3.38)	
Current smoker	0.61 (0.36 - 1.02)	1.53 (0.81-2.89)	1.87 (0.84-4.15)	0.91 (0.27 - 3.12)	
Ever alcohol use	1.51 (0.99-2.32)	0.80 (0.47-1.33)	0.52 (0.26-1.02)	1.23 (0.48-3.16)	
	. ,	· /	· /	· /	

\*Adjusted for all variables, except race-specific models not adjusted for race.

The overall yield among women invited to enrol into the CGN was 15% for African Americans and 36% for Whites. That only a subset of CBCS participants enrolled in the CGN is due in part to the time lag (>5 years) between their participation in the CBCS and the CGN invitation. The longer the time between contacts, the more likely women will have died, become too sick to participate, or be lost to follow-up.

Lower enrolment rates among African American women compared with White women reflect both lower contact rates (due to more deceased and unlocatable women) and lower cooperation rates among those contacted. The higher proportion of deceased women reflects that African American women are diagnosed, on average, with later-stage breast cancer than White women (15, 16). The higher proportion of unlocatable women is consistent with other studies showing that recontact and continued participation rates are lower among minorities (17, 18). Suggested explanations include a greater propensity among lower-income individuals to change residences and telephone numbers.

Among women contacted, the magnitude of the difference in enrolment rates between African Americans and Whites (37% and 58%, respectively) was quite remarkable, considering that all women had previously participated in a research study. The racial difference was more striking than in the CBCS, in which cooperation rates were only  $\sim 5\%$  lower among African Americans than Whites (1). The fact that African American women were so much less likely to enrol suggests there may have been aspects of the CGN registry that made it less appealing to potential participants than the original study.

Lower enrolment rates among African Americans may have reflected the type of study and differences in perception of the CGN as compared with the CBCS (e.g., purpose, benefit, burden, and risk). The purpose of the CBCS was to study risk factors for breast cancer, a disease that had immediate salience to participants due to their recent diagnosis. Under these circumstances, the relevancy of the research was obvious and may have overcome barriers to participation, including feelings of mistrust. In contrast, the immediate relevancy of the CGN registry to the women may have been less obvious. It is also possible that the focus on genetics raised more concern among African American than White women. Although the CBCS evaluated genetic risk factors, the emphasis of the study was on understanding a broad spectrum of risk factors. In contrast, the primary focus of CGN is on family history and genetic characteristics. In unpublished findings from discussion groups with minority and White women, non-Whites seemed to be more concerned about negative consequences of genetic testing such as family conflict, anxiety, and limited usefulness.<sup>5</sup> Hence, the potential risks may have outweighed potential benefits of genetic research in the minds of African American women, and this may have influenced their decision to decline CGN enrolment.

The perceived burden for participation relative to the benefits may have differed between the CBCS and the CGN. Whereas the CBCS required only a one-time interview, CGN enrolment involved a baseline interview plus annual recontacts to update personal and family information. The basic requirement that participants provide a detailed family history of cancer may have deterred enrolment among some African American women, given that African Americans are less likely to have traditional family structures (19). In addition, potential participants were told that the CGN may contact them about participating in other studies, which creates some element of uncertainty about what being in the registry would lead to in terms of future involvement. This uncertainty about future expectations may have contributed to the relatively low recruitment. However, it is not clear how or why these perceptions should have differed by race.

Other differences between the CBCS and the CGN also may have accounted for the low participation rates overall and among African Americans in particular. In the CBCS, women were told that their physicians had given consent for the study to contact them. Physician recommendation has been reported to be an important determinant of several health-related behaviors (20-22) and may have enhanced response rates for the CBCS as compared with the CGN, in which there was no physician contact. Another difference was that the CGN offered no monetary incentive for participation. Although a previous article (11) reported that a relatively small proportion of CBCS participants cited the incentive as a reason for participation, the effectiveness of incentives in enhancing response rates is well documented (23, 24). Incentives may be particularly important in conveying the message that investigators value information provided by participants, and they are not expected to give something without getting something in return. To our knowledge, there are no published data comparing the effectiveness of physician recommendation or monetary incentives in enhancing response rates among Whites and African Americans.

Our analyses showed that, among women who had previously taken part in a research study, CGN enrolment was significantly lower among African Americans than Whites. We had expected similar enrolment rates across both races because all women had been diagnosed with breast cancer, were somewhat familiar with research, and previously had taken part in an epidemiologic study. Racial differences could not be explained simply on the basis of socioeconomic characteristics, as race remained the only significant predictor of enrolment when taking education, occupation, and income into account. The lack of association between socioeconomic factors and CGN enrolment was surprising given that socioeconomic status is presumed to be a major explanatory variable for lower participation rates among minorities. We identified no other factors that seemed to explain the lower enrolment rates among African Americans. This suggests that African Americans' lower participation rates may be due to less tangible differences in attitudes and perceptions about research variables not assessed in this study. The fact that all invited women had previously participated in a study of breast cancer suggests that enrolment in a cancer genetics registry may have raised particular concerns for African Americans. These may be issues related to family involvement or to research involving genetics. Additional research among African Americans is needed to understand attitudes or concerns that act as barriers to participation in studies of genetics and cancer.

<sup>&</sup>lt;sup>5</sup> Dr. Beth Newman, personal communication.

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