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Cohort profile: the longitudinal National Growth and Health Study (NGHS) of black and white girls from Northern California tracking how behavioural and psychosocial risk factors predict cardiovascular risk and biological ageing in midlife and in offspring

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ABSTRACT

Purpose The National Heart, Lung and Blood Institute Growth and Health Study (NGHS) prospectively collected anthropometric, biospecimens, clinical, health behaviour and psychosocial measures associated with cardiovascular disease from childhood to young adulthood. The aim of the current study was to assess the impact of stress, dysregulated eating and social genomic biomarkers on cardiometabolic risk factors among the original participants now in midlife and their children.

Participants Beginning in 1987–1988, NGHS recruited black and white girls (age 9–10 years) from socioeconomically diverse backgrounds from from three sites: Cincinnati, Ohio; Washington, DC; and Western Contra Costa County, California (N=2379) and followed them for 10 years. The study maintained an 89% retention rate. The current study is 30 years after the start of the original study and focused on the participants of California (n=887) and their children aged 2–17 years. We re-enrolled 624 of 852 eligible participants (73%): 49.2% black and 50.8% white. The mean age was 39.5 years. Among the 645 eligible biological children, 553 were enrolled; 49% black and 51% white, with 51.5% girls and 48.5% boys. The mean age was 9.3 years.

Findings to date Longitudinal analysis of adolescent drive for thinness predicted higher scores for drive for thinness during midlife, which was indirectly associated with greater adult body mass index through adult drive for thinness. Latent trajectory modelling of adolescent growth over 10 years found that women with persistently high weight trajectory had twice the odds of having children who met the definition for obesity compared with the persistently normal group, adjusting for adult weight.

Future plans New studies on neighbourhood socioeconomic status, food insecurity and additional biomarkers of chronic stress, microbiome and accelerated ageing (ie, telomere length and epigenetic clock) are underway. We are developing a 10-year follow-up to understand changes in ageing biomarkers of the participants and their children.

Trial registration number NCT00005132.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ There is limited research on childhood and adolescent predictors of cardiovascular disease (CVD) risk among women at midlife.
⇒ Racial and social disparities in CVD risk must be viewed with a life course perspective; the National Heart, Lung and Blood Institute Growth and Health Study (NGHS) cohort spans more than 40 years.
⇒ Extensive recruitment and retention efforts were implemented to revive the NGHS cohort after 20 years; 73% of the eligible participants were successfully enrolled.
⇒ A wide range of sociodemographic, economic, health behaviour, psychosocial and life stress, clinical and anthropometric measures were obtained to create a comprehensive assessment of risk factors.

INTRODUCTION

Chronic diseases are the leading cause of death and disability in the USA,[1] yet their origins are not well understood. Such conditions develop gradually, rendering cross-sectional epidemiological studies ineffective at assessing specific exposure–outcome relationships. Cardiovascular disease cohorts starting in young adulthood, including the Framingham Heart Study,[2] Coronary Artery

Risk Development in Young Adults,[3] Multi-Ethnic Study of Atherosclerosis,[4] and starting in childhood, the National Heart, Lung and Blood Institute Growth and Health Study (NGHS),[5] have overcome cross-sectional research limitations by tracking potential risk factors across the life course, broadening our understanding of complex causal relationships and the long-term impacts of various social phenomena. The NGHS was conceived to address racial/ethnic disparities in the development of cardiometabolic risk factors with attention to measures of growth and development, clinical markers of health, nutrition and health behaviours, stress and psychosocial risk factors.[5]

Continued participation in longitudinal cohorts is crucial for ensuring their contributions to the field. At least 70% retention is considered ideal.[6 7] Many longitudinal cohorts, especially those revived after long periods of non-contact, have relied on multiple recruitment strategies to maximise enrolment.[8] However, traditional methods—home mailings, telephone calls and face-to-face recruitment—are becoming less effective. For instance, making 10 telephone calls per potential participant was considered standard in the 1970s–1990s.[9] In recent years, researchers have reported up to 40 calls to reach participants, with additional efforts providing diminishing returns.[7]

A combination of traditional strategies (eg, mailing invitations, phone calls) along with barrier-reduction approaches (eg, parking reimbursement) and contemporary retention methods (eg, social media and study websites)[8] appears promising and has been associated with reductions in time, cost and participant burden, as well as 3–24% increases in participant response.[10 11] Barrier-reduction efforts, such as parking compensation, childcare and alternative methods for data collection, have been associated with a 10% increase in participant retention.[8] In the CUPS One World Study, researchers used Facebook to locate and recruit 16% of unresponsive participants who otherwise would not have participated.[12] Bolanos and colleagues likewise found that, used alongside mailings and phone calls, Facebook helped identify and enrol difficult-to-reach participants, who were younger, female, out of state or had mental health conditions.[13] Beyond these reports, however, little is known about the value of combining traditional and novel communication methods in longitudinal cohorts spanning several decades or generations. Understanding how to retain participants most effectively for such studies is critical as we work towards expanding our knowledge of chronic diseases.

This paper describes the recruitment and retention strategies, study protocol and demographic profile of a follow-up study to one site of the NGHS, conducted 30 years after the inception of the cohort, when there was little contact for the past 10 years. Between 1999 and 2005, collaborators worked with subsets of the cohort to investigate five topic areas: bone density, fibromyalgia, temporomandibular disorders, eating disorders and pregnancy. We recruited both original participants and their children, uniquely positioning this study to assess generational transmission of chronic disease risk. Our primary research questions were: (1) to what extent are life stress and dysregulated eating independently associated with change in adiposity and cardiometabolic risk factors among NGHS participants through age 40 years; (2) to what extent are maternal early life and cumulative stress and dysregulated eating associated with adiposity and cardiometabolic risk factors in the children of the NGHS cohort; and (3) do these relationships of maternal early life and cumulative stress and dysregulated eating significantly differ by ethnicity or by socioeconomic status?

COHORT DESCRIPTION

Study design and original sample

The original NGHS examined risk factors for cardiovascular disease.[5] Annually, researchers collected anthropometric measurements, biospecimens, clinical examinations, diet and physical activity records, eating behaviour, and other lifestyle information from black and white, socioeconomically diverse girls from childhood (age 9–10 years) through young adulthood (age 19–20 years). They were recruited from three regions of the USA: Western Contra Costa County in California, Cincinnati and Washington, DC (N=2379). Building on longitudinal data from participants from the Western Contra Costa site (n=887), the current wave assesses their health at age 37–43 years. We have enriched the cohort by inviting biological children to participate with their mothers to examine the transgenerational transmission of disease risk. The original NGHS, beginning in 1987–1988 and continuing through 1997–1998, maintained an 89% retention rate throughout the 10-year study period.[14]

Since the 10 years of annual assessments ending in 1998, collaborators worked with subsets of the cohort to investigate five topic areas between 1999 and 2005: bone density, fibromyalgia, temporomandibular disorders, eating disorders and pregnancy. In 2015, the present follow-up study was funded to address race, stress, dysregulated eating and metabolic health. This was the first follow-up study in 10 years that attempted to contact the full California cohort. All procedures were approved by the Committee on Human Research of the University of California, Berkeley.

Current study recruitment efforts and participant characteristics

A woman was eligible to enrol in the current wave if she was: (1) an original NGHS participant; (2) not pregnant at the time of recruitment, and had not experienced a pregnancy, miscarriage or abortion within the last 3 months; and (3) not living abroad, nor incarcerated or otherwise institutionalised. Participants' biological children were eligible if they were between the ages of 2 and 17 years. Five participants were removed from the historical data after the first year of the original study, rendering a recruitment sample of 882.

Recruitment efforts

Strategy 1: batch mailing and telephone follow-up

Initial invitations were mailed between January 2016 and March 2017. Follow-up calls began in March 2016 and continued through May 2017. The study team included two full-time, four part-time and one to four volunteers at any given time. Online databases, such as WhitePages Pro, LexisNexis and Family Tree Now, were used to manually search individual participants to obtain residential addresses and telephone numbers. We mailed invitations to all 882 participants in batches of 100 after which we conducted follow-up calls.

Strategy 2: second mailing and targeted calling

In June 2017, we ran another database search for the updated contact information of the 533 unenrolled participants. After successful phone outreach during strategy 1, we developed a targeted calling protocol. Between September 2017 and June 2018, we conducted up to 15 phone calls, on a rotating schedule, and left two voicemails for each participant.

Strategy 3: social media and electronic outreach

From June 2017 to May 2019, our team focused on electronic outreach for the remaining 345 non-responsive participants with:

- Social media accounts/sites: NGHS Today Website, NGHS Today Facebook page with regular posting and NGHS Today LinkedIn.
- Individualised participant searches using social media (Facebook), Google, WhitePages and Family Tree Now.
- Email domain change campaign: LexisNexis provided up to five 'best' email addresses. We used these and changed the domain, replacing each with gmail.com, hotmail.com, aol.com and yahoo.com.
- Text message campaign.
- Targeted mailing and follow-up telephone calls to participants' mothers.
- Referrals from friends and family.

Strategy 4: door-to-door outreach

From January to May 2019, we attempted to reach 75 non-responsive participants living in the Bay Area. We confirmed their last locations of residence using our database search platforms, as well as information gathered from family members and friends. We visited 16 geographical clusters of addresses on 15 Saturdays between January and May 2019, knocking on 176 doors in total. Our travel team was prepared to enrol participants and complete the full protocol on the spot.

Barriers to enrolment

Throughout the study, we spoke with many women who were not able to enrol. Common reasons were distance from the study site, lack of time, resources and interest. We learnt from these barriers and made strong efforts to accommodate our participants with flexibility for remote participation, and additional compensation for travel and time spent participating.

The initial mailing and follow-up call (January 2016–May 2017) resulted in 321 (36.4%) participants enrolling in the study. The targeted telephone outreach and social media efforts (March 2017–June 2018) resulted in 157 (17.8%) additional participants being enrolled. During the final year of recruitment (January 2018–September 2019), an additional 146 (16.6%) were recruited through a variety of concurrent efforts including traditional recruitment methods, outreach through friends and family, social media and targeted internet communications. Table 1 displays the recruitment method by which participants were enrolled. There were no differences by race for the method of recruitment that resulted in participant enrolment.

Participant characteristics

Table 2 shows the participant status among the 882 original NGHS participants. Thirty women (3.4%) were ineligible because they were deceased (n=20), lived abroad (n=3), incarcerated or institutionalised (n=3), or lost to follow-up after year 1 of the original study (n=4). Among those who were eligible, 48 (5.4%) declined to participate, 47 (5.3%) were contacted and showed interest but never enrolled, 133 (15.1%) were never reached and 624 (70.8%) were enrolled (figure 1). Using the Response Rate 3 formula (page 62) from the American Association for Public Opinion Research calculations (2016), we estimated a 73.8% retention rate among those eligible. The formula is RR3=I/I+(R+NC)+e(UO); where I is the number of respondents with an interview, R is the number who refused, NC is the number of non-complete after initial contact and UO are unknown. The estimate (e) of ineligible among the unknown is calculated by calculating the proportion of ineligible among those contacted. Therefore, e=30/719=0.042, and the RR4=624/(624)+(48+47)+(0.042×133)=73.76%. Those who participated were more likely to be white (51% vs 42%), come from a two-parent household (67% vs 56%), have a higher per cent of parents who were college graduates (32% vs 22.5%) and have a family income greater than $40 000 (34% vs 22.8%) at baseline, compared with those who were eligible but did not participate. There was no difference in the number of children in the household at baseline.

Of the 624 participants, 97 women (16%) had no children. The 527 participating mothers self-reported a total of 1263 biological children with ages ranging from newborn to 26 years old; only 403 mothers (64.5%) had children who were eligible. Among participants' biological children, 429 children did not meet the age criteria, either being too young (N=68) or old (N=361) for the protocol. We had no information regarding birthdate or age for 95 children, thus rendering them ineligible. In September 2017, due to feedback from participants regarding study complexities, we limited the study to one child, and thus 94 participants were ineligible. The remaining 645

Table 1 Method of recruitment that resulted in participant enrolment into the study: number and per cent of participants in the NHLBI growth and health follow-up study (N=624)

Recruitment method	Number (%)	Black	White
Traditional methods	474 (76.0)	229 (64.8%)	245 (77.3%)
Mail invitation	277 (44.4)	120 (39.1%)	157 (49.4%)
Follow-up phone call	181 (29.0)	104 (33.9%)	77 (24.4%)
Follow-up text	16 (2.6)	5 (1.6%)	11 (3.5%)
Outreach through friends and family	59 (9.5)	29 (9.4%)	30 (9.5%)
Another participant	19 (3.0)	9 (2.9%)	10 (3.2%)
Family member	11 (1.8)	6 (2.0%)	5 (1.6%)
Mother mailing	11 (1.8)	4 (1.3%)	7 (2.2%)
Door knocking	18 (2.9)	10 (3.3%)	8 (2.5%)
Social media and web	91 (14.6)	49 (16.0%)	42 (13.2%)
Follow-up email	53 (8.5)	24 (7.8%)	29 (9.2%)
Facebook	23 (3.7)	14 (4.6%)	9 (2.8%)
NGHS website	15 (2.4)	11 (3.6%)	4 (1.3%)
LinkedIn	0	0	0
Total	624	307 (49%)	317 (51%)

No difference was found for recruitment method by race (Pearson X^2=0.94 p=0.63).
NGHS, National Heart, Lung and Blood Institute Growth and Health Study; NHLBI, National Heart, Lung and Blood Institute.

children met the eligibility requirements at time of enrolment. Of these, 553 enrolled in the study (86% of the eligible child participants); 6 opted out of the study and 86 were lost to follow-up. Table 3 describes the number and percentage of children who enrolled by gender and race. Similar to the original participants, roughly 30% of children completed the protocol remotely.

Patient and public involvement

Participants and the public were not involved with the design of the study or research questions. The study began in 1987 to follow a cohort of young white and black girls to identify disparities in cardiovascular disease risk. Most of the study design and data elements are repeated over time. Participants did, however, assist with recruitment and enrolment, provided feedback on data collection that was burdensome and assisted with implementation of more efficient data collection efforts.

Study protocol

The study protocol consisted of pre-visit, visit and post-visit activities designed to be flexible to accommodate diverse life circumstances. The three study parts included a baseline survey, in-person home/clinic visit and post-visit biospecimen collection. For those living out of state, we offered a 'remote option' using a long-distance protocol. After completing the consent process, we collected all further data by mail or phone. The three-part protocol was estimated to take 5–7 hours to complete over the course of 1–6 months. Eighty-two per cent (N=511) of enrolled participants completed part 2 of the protocol; approximately 41.7% with a clinic visit at University of California, Berkeley, 25.6% with a home visit and 32.7% via a remote protocol using mailed study materials.

Baseline survey

The 45-minute baseline survey was completed online or on paper, and included sociodemographic information about the participant and her children, as well the following scales:

- Perceived Stress Scale.[15]
- United States Department of Agriculture (USDA) 18-item Household Food Security Scale.[16]
- Past Food Security.[17]
- Eating Disorder Inventory-3 (EDI).[18]
- Reward Based Eating Drive.[19]
- Rosenberg Self-Esteem Scale.[20]

Table 2 Participation status of women by race (N=882)

	Ineligible	Declined	Contacted, not enrolled	Unable to contact	Enrolled
Total	30 (3.4%)	48 (5.4%)	47 (5.3%)	133 (15.1%)	624 (70.8%)
Black	14	28	25	81	307 (34.6%)
White	16	20	22	52	317 (35.6%)

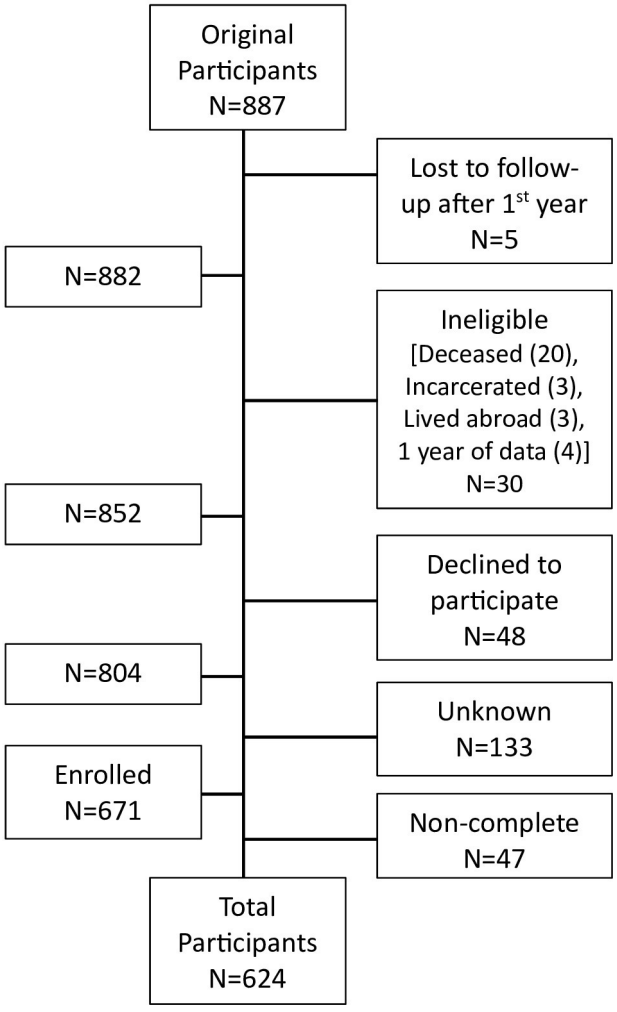

Figure 1 Flow diagram of NGHS participants. NGHS, National Heart, Lung and Blood Institute Growth and Health Study.

Table 3 Characteristics of child participants by race and protocol location (N=553)

	Eligible	Enrolled
Total	645	553
Girls	324 (50.2)	285 (51.5)
Boys	321 (49.8)	268 (48.5)
By mother's race		
Black	315	270
Girls	160 (50.8)	133 (49.3)
Boys	155 (49.2)	137 (50.7)
White	330	283
Girls	163 (49.4)	151 (53.4)
Boys	163 (49.4)	131 (46.3)
Missing	4 (0.01)	1 (0.004)

- Physical Health Center for Disease Control, Behavioral Risk Factor Surveillance System (BRFSS) Questionnaire.[21]
- Center for Epidemiologic Studies Depression Scale.[22]
- Stanford Brief Physical Activity.[23]

Participants were compensated $50 on a prepaid Visa card for completing their survey and this Visa card was given to the participant during the next part of the study.

In-person home/clinic visit or remote option

We offered two in-person options for local participants to provide body measurements: (1) a home visit for women within 65 miles of Berkeley, California or (2) a clinic visit for any woman able to come to Berkeley with her children. Participants received their compensation, which varied ($50–175) by participation level, at the end of this visit. The visit protocol was conducted by two team members and included consent, anthropometric measurements, a blood pressure reading, 3-day food and physical activity record training, and blood draw appointment scheduling. Each participating child completed anthropometry and blood pressure measurements. Children 9.5 years or older completed a child survey.

For participants who could not complete an in-person visit, a remote option was offered. For ease of participation, the remote protocol asked that only one child (preferably the youngest child) participate in the study. Participants were sent a package including anthropometric measurement tools, a 3-day food and physical activity record, a blood draw scheduling form, applicable surveys and a Visa gift card. During a phone call, package contents were reviewed, study staff assisted with mother and child body measurements, scheduled a blood draw appointment and trained participants on completing the 3-day diaries. YouTube video tutorials made by our staff were provided for additional guidance.

Blood pressure measurement

Three readings of systolic and diastolic blood pressures were recorded among local participants and their children between the ages of 10 and 17 years, following the National Health and Nutrition Examination Survey (NHANES) protocol.[24]

Anthropometric measurements

Weight, height, waist circumference and hip circumference measurements were collected from each local participant and her participating children between the ages of 2 and 17 years using the NHANES protocol.[24] Sagittal abdominal diameter was collected per what protocol.[25] Measurement tools differed between local and distant participants. Distant participants measured their height, weight, hip and waist circumference, following precise real-time verbal and printed instruction. For local participants, staff members were responsible for taking measurements from both participants and their eligible children. All participants and their children were instructed to wear loose, stretchy clothing. Each anthropometric measure was taken three times for both local and distant participants.

Children's surveys

Children over the age of 9.5 years completed a boy's or girl's survey. All items were similar between the surveys except for the pubertal development questions. The survey took about 25 min and included items:

- Demographic information.
- General health, smoking and weight.
- Perceived Stress Scale.[15]
- Children's Depression Index.[26]
- Child Food Insecurity.[27]
- EDI.[18]
- Sleep schedule/sleep deprivation.[28]
- Pubertal development.[29]

Part three

After completing the in-person visit or the remote options, participants attended their blood draw appointment and completed their 3-day food and physical activity record. The 3-day records were mailed back to the NGHS office and checked by staff for completion. Team members corrected incomplete records with participants over the phone.

Statistical analysis

We conducted descriptive statistics generating mean, SD, percentages and X^2 for categorical variable, and t-test for continuous variables in STATA V.14 (Stata Statistical Software: Release 14. College Station, Texas, USA: StataCorp).

Participant characteristics are shown in table 4. NGHS participants enrolled were 49.3% black and 50.7% white. White participants had higher education, higher income, and a greater percentage were married or living with a partner. There were no differences by race in the number of children. Black participants had a greater past and current food insecurity score. White participants scored significantly higher on disordered eating behaviour measures and reported more moderate and vigorous activity. No differences were found by race for perceived stress, depressive symptoms or perceived health status.

FINDINGS TO DATE

The original NGHS led to over 170 publications about childhood health, lifestyle and race/socioeconomic factors. For example, it was one of the first studies to reveal race differences in central adiposity,[30] insulin resistance,[31] body satisfaction[32] and emotional eating,[33] among young black and white adolescents. At baseline aged 9 or 10 years, black girls had lower triglycerides and higher high-density lipoprotein cholesterol, while higher body mass and blood pressure than their white counterparts.[5] By the end of the original 10-year study period, mean cardiovascular health scores declined. Based on two points for each of the following seven metrics: physical activity, dietary intake, smoking, body mass, blood pressure, fasting cholesterol and fasting glucose, 17% of white and 23% black girls had cardiovascular health scores below 8 by age 20 years.[34] In addition, we have found that chronic stress during childhood[35] and lower physical activity levels[36] led to greater body mass index (BMI) at age 19/20 years. Eating behaviour measures of body dissatisfaction, drive for thinness, perfectionism, bulimia, anxiety and emotional eating were found to be among the most important constructs that explained the 10-year change in BMI.[37] Among black participants, we found that lower skin colour satisfaction at ages 13 and 14 years significantly predicted greater odds of binge eating disorder and lower skin colour satisfaction at all ages predicted greater binge eating disorder symptoms. Body satisfaction mediated the relationship between skin colour satisfaction and binge eating disorder symptoms. Our results suggest that skin colour dissatisfaction is a novel component of body image for black girls that is also related to binge eating.[38]

Findings from the current study include the longitudinal analysis of adverse childhood events, eating behaviours and weight gain trajectories on dietary intake and cardiometabolic risk. We tested the moderating influence of diet on the relationship between adverse childhood events and depression at midlife and found that women who did not experience adverse child events had a strong inverse association between diet quality and depression symptom prevalence.[39] Using structural equation modelling, we found adolescent drive for thinness predicted higher scores for drive for thinness during midlife, which in turn led to greater adult BMI in adulthood.[40] Using latent trajectory modelling to identify weight trajectories over the 10 years of adolescence, four patterns emerged: weight loss then gain, persistently normal, persistently high BMI and weight gain then loss. Women who had a persistently high BMI trajectory during their adolescence had twice the odds of having children who met the definition for obesity compared with the persistently normal group, adjusting for adult BMI.[41] Taken together, these findings suggest that stress and adverse eating behaviours that persist over the life course influence health for women and their children.

Strengths and limitations

We were able to identify and contact the majority of original NGHS cohort participants from the Western Contra Costa County, California site 10 years after the last study. We successfully enrolled equal percentages of black and white women from the original cohort, on average the current participants were from a slightly higher socioeconomic background compared with their baseline socioeconomic characteristics at age 9/10 years. Furthermore, we were able to enrol the majority of eligible biological children.

Innovative recruitment strategies: our successful recruitment that resulted in enrolling over 73% of eligible participants relied on a variety of recruitment and retention methods over a 3.5-year period. While a majority of participants were recruited using traditional methods—mail, telephone and text messages—over 26% of participants were recruited through novel outreach methods

Table 4 Characteristics of female participants by race, number and percentage of participant characteristics by protocol and race

Variable	Total N=624	White N=316 (50.7%)	Black N=307 (49.3%)	P value
Education (N, %) (N=623)				<0.001
High school or less	135 (21.7)	51 (16.1)	84 (27.5)	
Some college	252 (40.4)	103 (32.5)	149 (48.7)	
College or more	236 (37.9)	163 (51.4)	73 (23.8)	
Income (N, %) (N=584)				<0.001
$<30 000	114 (19.5)	40 (13.1)	74 (26.5)	
$30 000–49 999	83 (14.2)	28 (9.2)	55 (19.7)	
$50 000–89 999	167 (28.6)	80 (26.2)	87 (31.2)	
$90 000+	220 (37.7)	157 (51.5)	63 (22.6)	
Marital status (N, %) (N=614)				<0.001
Single/never married	176 (28.7)	40 (12.7)	136 (45.6)	
Married/living with partner	341 (55.5)	226 (71.5)	115 (38.6)	
Separated/divorced/widowed	97 (15.8)	50 (15.8)	47 (15.8)	
Number of children (mean, SD) (N=623)	1.5 (1.3)	1.5 (1.2)	1.5 (1.3)	0.97
Past Food Security (mean, SD)* (N=620)	0.8 (1.4)	0.7 (1.3)	0.9 (1.5)	0.02
Current food security (N=594)				0.04
High	476 (80.1)	255 (83.3)	221 (76.7)	
Marginal	23 (3.9)	14 (4.6)	9 (3.1)	
Low	48 (8.1)	17 (5.6)	31 (10.8)	
Very low	47 (8.0)	20 (6.5)	27 (9.4)	
Drive for thinness (N=618)	9.4 (7.3)	10.4 (7.8)	8.3 (6.6)	<0.001
Reward Based Eating Drive (N=619)	0.8 (0.8)	1.0 (0.8)	0.6 (0.7)	<0.001
PSS (mean, SD) (N=620)	17.6 (6.8)	17.7 (6.7)	17.4 (7.0)	0.59
CES-D depressive symptoms (N=610)				0.83
Depressed	388 (63.6)	201 (64.0)	187 (63.2)	
Not depressed	222 (36.4)	113 (36.0)	109 (36.8)	
Rosenberg Self-Esteem (N=611)				<0.001
Low	68 (11.1)	54 (17.3)	14 (4.7)	
Normal	333 (54.5)	185 (59.1)	148 (49.7)	
High	210 (34.4)	74 (23.6)	136 (45.6)	
Self-reported health status (N=612)				0.08
Excellent	45 (7.4)	22 (7.0)	23 (7.8)	
Very good	166 (27.1)	90 (28.5)	76 (25.7)	
Good	236 (38.6)	126 (39.9)	110 (37.2)	
Fair	130 (21.2)	68 (21.5)	62 (20.9)	
Poor	35 (5.7)	10 (3.1)	25 (8.4)	
Physical activity (N=609)				<0.001
Didn't do much	92 (15.1)	29 (9.4)	63 (21.1)	
Light activity—1–2 times/week	193 (31.7)	92 (29.7)	101 (33.8)	
Moderate activity—3–5 times/week	242 (39.7)	140 (45.2)	102 (34.1)	
Vigorous activity—5+ times/week	82 (13.5)	49 (15.8)	33 (11.0)	

*Derived from an adapted five-item Past Food Security[17] scale measuring food security between ages 5 and 11 years.
CES-D, Center for Epidemiologic Studies Depression Scale; PSS, Cohen's Perceived Stress Scale.

and social media. We found women aged 38–43 years are digitally present, and respond to diverse forms of contact, including text, social media outreach and email. We employed over 10 recruitment strategies, often using multiple strategies at the same time. These strategies offered flexible response options and timely reminders, and were often viewed as less burdensome.

We focused primarily on the three new strategies—social media, email campaign and personal outreach—after the first year of recruiting but continued to simultaneously implement traditional methods. Our electronic strategy was to create an online and easily findable presence with several social media accounts using Facebook, LinkedIn and an NGHS website. We created both a Facebook profile and a separate Facebook page, using the profile to connect directly with participants by sending them 'friend requests' and using the page as a platform for meaningful engagement. In addition to study updates and recruitment information, we posted images from past waves, appropriate and fun messaging around holidays and, with permission, pictures of their children's art from our in-person visits. Using social media as a platform for recruitment, we enrolled 6% of our participants. Our second focus area was an email campaign created by changing the domain endings for all the email addresses we received from LexisNexis. Each email address was changed seven times to reflect the most used email platforms. We enrolled an additional 9% of our participants using the domain change method. The final focus area was on community outreach based on information that friends and family members provided, which we confirmed using a WhitePages Pro search to complete detailed profile for each participant. We sent text messages, phone calls and Facebook messages to these individuals, and visited their communities using a door-to-door protocol to ask neighbours and acquaintances for participant contact information. Using community outreach, we were able to enrol an additional 9% of participants. Our success during the final year of recruitment was not attributed to one specific outreach strategy but rather using all strategies in tandem. Given the importance of each participant, we endorse the need to take extra time to try different outreach methods.

Two important aspects bolstered these enrolment strategies. On the research team side, we hired diverse staff members who were culturally congruent with the study population. We know that this was very important for in-person visits and during door-to-door outreach. We found that flexibility, accommodations and constant participant engagement, both in person and virtually, encouraged participants to not only enrol but complete all aspects of the three-step protocol. On the participant side, we received consistent feedback from participants who enrolled that the numerous outreach efforts served as reminders that the study was ongoing and readied them to finally enrol. We recommend that future cohort follow-up studies to not only begin with traditional approaches such as mail invitation and telephone calls, but to employ novel approaches from the beginning that facilitate ease of participation through secured internet sites and social media.

Examination of race differences in a modern light: the NGHS was designed to examine the development of race differences in health. We now know that the construct of race is not biological but a socially constructed and cultural character of individuals,[42 43] whether self-identified or assigned by research staff. Therefore, since race is not biologically based, the focus of our analyses is not about genetic differences. The new NGHS wave can interpret differences in the light of lived experience of people based on their ethnicity. Consequently, the lived experience reflects the experience of systemic racism and discrimination.[44]

We plan to learn about ethnic differences without attributing to biology but rather understanding the socioecological context. We will note when there are group differences or when ethnicity moderates a finding. We will then test for discrimination as a potential explanatory factor, when appropriate. Lastly, we will examine all hypotheses within group, so that we are not reifying the false need to have a white control group.

Collaboration

We have revived an established cohort of women and added another generation of participants. We encourage use of the longitudinal data and are open to collaborations, especially in the areas of dietary intake, eating behaviour, stress, metabolism, cardiovascular risk and biological ageing. The historical data are publicly available through the National Institutes of Heart, Lung and Blood Biologic Specimen and Data Repository.[45] The data used for the current study are not publicly available, but de-identified data may be available on request, subject to approval by the internal review board and under a formal data use agreement and based on scientific merit. Please contact the principal investigators BL (blaraia@berkeley.edu) or EE (elissa.epel@ucsf.edu).

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Contributors BL accepts full responsibility for the work and the conduct of the study as guarantor, had access to the data, and controlled the decision to publish. BL, KB, RF, EB and EE conceived the present analysis and manuscript. BL, KB, RF, RP, EB, IF and SC contributed to data collection and drafted the manuscript, with

contributions from SEM, LDR and EE. BL, LDR and EE designed and established the NGHS cohort, and are also responsible for their continued management. EB and BL performed the data analysis. BL and EE obtained funding for the NGHS cohort. KB, RF and EB were responsible for data management. All authors reviewed, critically revised and approved the manuscript.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not required.

Ethics approval This study involves human participants and was approved by the University of California, Berkeley (reference number 2013-11-5774). Participants gave informed consent to participate in the study before taking part.

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Data availability statement Data are available in a public, open access repository. Data are available upon reasonable request. Historical data are publicly available at https://biolincc.nhlbi.nih.gov/. The data used for this study are not publicly available, but de-identified data may be available on request, subject to approval by the internal review board and under a formal data use agreement. Please contact the principal investigators BL (blaraia@berkeley.edu) or EE (elissa.epel@ucsf.edu).

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