UNDERSTANDING THE CHALLENGES IN RECRUITING BLACKS TO A LONGITUDINAL COHORT STUDY: THE ADVENTIST HEALTH STUDY

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This paper presents findings from formative research exploring Black Seventh-day Adventist church members' attitudes about Black nonparticipation in past studies, and suggestions for recruiting 45,000 Blacks to an upcoming longitudinal cohort study. Data were collected in California and Pennsylvania, using 15 key informant interviews and 6 focus groups. Key findings supported and elucidated existing literature on the barriers to minority recruitment, and included: a general mistrust of the medical/scientific community; a perception that providing informed consent relinquishes, rather than protects, an individual's rights; a perception of being ''studied'' rather than ''studying,'' due to the paucity of Black investigators; and a perceived lack of cultural sensitivity in the recruitment of Blacks, and in the conduct of the research itself. Building trust throughout the process, from clearly demonstrating the benefits of participation, at the individual and community level, to including Blacks in the study design from conceptualization to data analysis and presentation, emerged as a critical component in garnering Black participation in future studies. (*Ethn Dis.* 2004;14:423–430).

Key Words: Minority Recruitment, African Americans, Cohort Study, Blacks

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INTRODUCTION

Cancer is the second leading cause of death in the United States, claiming more than half a million lives in 1999.[1] Obesity, in conjunction with its contributing factors of poor nutrition and physical inactivity, is poised to surpass tobacco as the leading contributor to US cancer mortality.[2] Blacks generally suffer disproportionately from cancer, as reflected in their higher incidence rates of colon and prostate cancer,[3–5] and poorer survival rates for breast cancer,[6,7] compared to other ethnic groups. However, we know little about the reasons for this variance in cancer risk between White and Black American populations. Only large-scale, parallel-designed studies can answer these questions.

Studies about lifestyle choices among Seventh Day Adventists have been conducted since 1958 (eg, Beeson et al[8]; Fraser[9]; Phillips et al[10]), providing much insight into the relationship between nutrition and health. Religious beliefs advocating an ovo-lacto vegetarian diet, physical activity, and substance avoidance, make this population ideal for study. Separating the protective or deleterious effects of consumption of certain foods or substances, and participation in physical activity, from other cultural and personal differences, is critical in explaining international and intra-national differences in cancer distribution. Cross-cultural comparisons and migration studies have provided robust and consistent evidence for the contribution of lifestyle to cancer risk.[11]

However, Black Adventist study participation rates in the past have been too low to allow for adequate ethnic-specific investigation of these issues. Despite the fact that we have successfully included Black members in some research and publications,[12–16] and that the Black Adventist leadership has expressed overwhelming support of this research, recruitment of Black church members has been difficult. Certain attributes of past efforts to engage Black members in these studies, as well as the challenges to minority recruitment faced by most researchers, contribute to this lack of engagement. Although White and Black Adventists share a common religion, the ways these religious beliefs are manifested is associated with cultural factors governed by traditional beliefs, feelings, attitudes, health practices, and historical and personal/familial experiences with the healthcare system,[4,5,17] which may affect willingness to participate in research studies.

A longitudinal cohort study, the Adventist Health Study-2 (AHS-2), has recently been funded, with a goal of recruiting 80,000 White and 45,000 Black Adventists. These populations were chosen because they represent large, potentially receptive study populations that can provide valid dietary and other lifestyle information, and that contain subgroups representing a wide variety of exposures to dietary and physical activity variables.[10] The purpose of this paper is to present findings from a formative research project qualitatively exploring Black Seventh-day Adventists church members' feelings and attitudes about their participation and nonparticipation in past studies, opinions regarding future participation, and suggestions for recruiting Black members into this longitudinal church-based study. The formative research was intended to inform the development of methods to recruit Black participants into this large cohort, and the integration of these findings into the AHS-2 recruitment approaches to the Black Adventist community is delineated. Implications of these findings for church-based and more general recruitment of Black populations into health promotion research are discussed.

REVIEW OF THE LITERATURE

Until recently, underserved racial/ethnic populations have been poorly represented in clinical trials, health promotion interventions, and observational epidemiological research.[4,5,18,19] We conducted a review of existing literature using the Medline electronic database, contacts with experts in the field, and citations from articles identified through these sources, to guide the efforts of this project toward our goal of understanding Black Adventist non-participation. We place the factors related to poor representation of Blacks in medical/scientific research studies into three general categories: 1) the conscious nonparticipation of Blacks; 2) physicians' failure to refer them; and 3) researchers/investigators' failure to recruit them.

Blacks' Conscious Nonparticipation

The literature reveals many reasons why Black Americans traditionally do not voluntarily participate in health-related research. At the top of the list is fear/mistrust of Whites.[18] This genuine fear of exploitation as research subjects is based on many historical accounts, from the slavery era and immediate post-slavery period, in which Blacks were operated upon without anesthesia, to the infamous and widely known Tuskegee syphilis experiment (1932–1972), in which government researchers withheld syphilis treatment from 399 Black men for more than 40 years.[5,20–22] A fear of genocide is another contributing factor for Blacks' nonparticipation in research studies. For example, Thomas and Quinn[23] reported that 35% of Blacks participating in their study believed that the sudden onslaught of HIV/AIDS signifies an attempt by Whites to rid society of Black people. Documented historical reports and memoirs handed down through generations (from elder family members and peers) substantiate these fears.[24]

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Swanson and Ward[5] cited "time and hassle" (ie, waiting time, travel time, participation time and energy) involved in participation, and a perception of little benefit being derived from participation, as other major factors for Blacks' reluctance to participate in research studies.

Traditional health beliefs (impacted significantly by their religious beliefs) also influence Blacks' involvement in research studies. The church is a vehicle in many Black families and communities through which religious beliefs assist in understanding, accepting, coping with, and managing disease and illness.[25] These beliefs often dictate alternatives to allopathic medicine, which are particularly attractive in the context of Blacks' lesser access to quality health care, particularly cancer care.[26] Similarly, Blacks' lack of belief in their susceptibility to cancer, or in allopathic medicine's effectiveness in preventing or treating it, may impede investment in clinical trial participation.[27]

Physicians' Failure to Refer Blacks to Clinical Trials

Another factor affecting Blacks' involvement in research is their lesser access to health care, and lower levels of health insurance coverage.[28] Reliance on emergency rooms and free/subsidized clinics compromises continuity of care, offering little opportunity for follow-up care, much less referral to clinical trials and research studies.[4,5,29] There is also evidence that physicians with predominantly minority practices are less likely to refer patients to academic institutions for trials, due to: fear that their relationships with patients will be undermined, since some of their patients have a distrust of academic medicine; inadequate resources to identify appropriate trials; or more urgent social needs of patients.[5,30]

Researchers' Failure to Recruit Blacks into Studies

Researchers' failure to recruit Blacks is another contributing factor to Blacks' low participation levels in health-related research. In fact, investigators typically have not consistently reported their recruitment efforts, successes, or failures, in the literature,[31,32] contributing to a general belief that Blacks are "hard to reach,"[33] and that recruitment and long-term retention of Blacks is difficult.[6] Another reason cited for investigators' failure to actively recruit Black participants is the increase in cost for minority recruitment, as monetary incentives and targeted strategies are often necessary.[34,35] This situation is changing, now that the federal funding agency requires that funded research include a plan for engaging and tracking underrepresented populations, in the absence of a strong justification for their exclusion.[36] However, the failure of most investigators' to establish positive and mutually beneficial ongoing relationships with Black communities[6,19,36–40] is still a substantial barrier.

METHODS

Subjects

Members of 3 predominantly Black Seventh-Day Adventists churches, 2 in Southern California, and one in Philadelphia, Pa., were recruited for qualitative data collection through verbal invitations and announcements by church members in support of the study. The churches differed in the size (300–1200) and socioeconomic make-up of their memberships. One church (Church A) is situated in a lower middle class suburban community, one (Church B) in an upper middle class suburban community, and the other (Church C) in a lower-income rural community. Overall, a total of 291 Black congregants in 3 churches (Churches B, C, and an additional church not included in qualitative data collection) were recruited to various dietary and physical activity survey measure validation pilot studies in preparation for the AHS-2 (data reported elsewhere). Any member of a Black Adventist congregation older than 30 years was eligible to participate. Church representatives were asked to invite 7–10 members to each focus group. Some of these individuals had participated in the pilot survey research, while others had not. Qualitative data were derived from 56 respondents during a 6-month period between December 1998 and June 1999, through 15 key informant interviews, and 6 focus groups. Focus groups ranged in size from 3–18 participants. Church A hosted a focus group with 1 man and 2 women. In Church B, 2 focus groups were conducted, one with 12 men and 6 women, and the other with 1 man and 3 women. In Church C, 3 focus groups were convened, with 4 men and 4 women, 3 men and 1 woman, and 5 women, respectively. The categories of respondents were: 1) pastors; 2) church leaders; 3) health and outreach workers; 4) regularly attending church members; and 5) a recruitment consultant specializing in Black studies. Percentages of respondents in each category are not available. Respondents included Black males and females between the ages of 29 and 65 years. The term "Black" is used to include individuals of African-American, Afro-Caribbean, and African descent. Those individuals who participated in quantitative data collection signed and returned consent forms along with their questionnaires; those who participated only in the qualitative data collection provided only verbal consent, as no personal identifying information was obtained from these members.

Procedures

While the content of the individual interviews and focus groups was similar, the individual interviews were used to identify and explore respondents' questions and concerns relating to their participation (actual or hypothetical) in medical research, in general, and epidemiological research, in particular, for further exploration in the focus groups. The interview began with general questions, and then follow-up questions and probes were utilized, as needed, to fully capture participant responses.

Individual interviews were conducted in English in a 45- to 60-minute, one-to-one, semi-structured format. With one exception, these were in private settings at the respondents' church. That exception was a telephone interview conducted in a similar format. The interviewer was a trained, doctoral-level Black faculty member (PH).

A detailed focus group discussion guide was created to assess 2 broad issues: participation in a future study, and perceptions of the planned survey instrument. With respect to the issue of participation in a future study, participants were asked about their familiarity with past studies, reasons for participation and non-participation in the past, barriers to, and facilitators of, participation, any previous experience with research, the role and meaning of incentives, and optimal recruitment strategies for their respective churches to the upcoming study (see Table 1 for domains and sample questions).

Focus groups were conducted in the multipurpose rooms of the participating churches. Sessions were not tape-recorded because when participants were explicitly asked at the beginning of the first focus group session about their levels of comfort with this procedure, several conveyed discomfort. Trained doctoral-level facilitators conducted the sessions, took notes and produced transcripts from these notes immediately after each session.

Cash incentives were provided to each church congregation as a whole ($500–$1000). Compensation of individuals for participation in this research, however, was one of the important questions to be addressed in the qualitative data collection process. While the scientific literature supports provision of such compensation in African-American religious settings, investigators had previously received conflicting advice from various church officials and opinion leaders about its appropriateness in an Adventist cultural context. For this reason, interviewees and focus group participants were not compensated for their time.

Data Analysis

Interview and focus group transcripts were produced after each session from facilitators' and observers' notes. Members of the research team independently analyzed the resulting transcript data using Grounded Theory methods.[41] First, the data were line coded to determine a universe of codes fitting the responses. These were then further analyzed to determine overriding themes. Data were then reorganized by themes and explored for their responses across participants. Finally, summaries were created for each emerging theme. Illustrative verbatim responses were included in each summary. Interview and focus group summaries were then aggregated and organized by theme.

Table 1. Domains and sample questions used in qualitative data collection

Interviews & Focus Groups	
Domain	**Sample Questions**
Familiarity with past studies	Have you ever heard of scientific research studies of Adventists? Give us your over-all opinion of these studies in general?
Reasons for past participation	Would you do it again? Why, or why not? What was your impression or feelings while completing the survey? How did you feel after completing the survey?
Reasons for past non-participation	If you did not participate, can you tell us why you chose not to? Why do you think others chose not to participate?
Barriers to participation	How did you feel after completing the survey?
Facilitators of participation	Give us some ideas for motivating or encouraging members to participate
Role and meaning of incentives	In your opinion, what would serve as good incentives or motivating factors for encouraging members to participate? Look over the proposed model for getting Black members to participate. Give us your opinion or any comments which you might have. Give us some ideas for participation incentives for both the questionnaire and the clinic.
Suggested strategies for recruitment	Do you have any suggestions for the best time(s) to hold group sessions? For example: before or after prayer meeting; Sundays (AM or PM) Do you have any suggestions for improving the recruitment process, the survey, or anything else? Do you have any suggestions for advertising and promotional strategies? Give us your honest opinion as to why you enrolled in the study? In other words, what motivated or encouraged you the most to participate? Give us your ideas for motivating or encouraging members to mail in the first half of their survey, or in some cases the full questionnaire.

RESULTS

Familiarity with Past Studies in the Church

While all respondents indicated that they were familiar with past studies, they were less clear about the contributions of these studies to the public health field in general, or their (potential) contributions to the body of knowledge about the health of Black Americans. They were familiar, however, with the fact that past studies involved largely White subjects. While a few had participated in the past, some respondents did not know that efforts had previously been made to recruit Black Adventists. A strong sense of mistrust of research and toward the research institution as a largely "White" institution was expressed. Participation was seen as something predominantly benefiting the "careers and pockets of researchers" and research institutions, and not as something of any immediate, or even delayed, benefit to them. In the words of one individual, "These White people are always trying to take from us what they can get, but what do they give us in return? After they get what they want they're gone." In addition, cynicism toward the university base of these studies as an extension of the "White" church was voiced. Many felt that the university and its researchers did not respect Black members.

Explanations for Participation and Non-Participation in Past Study Efforts

The few respondents who had participated in the past indicated that they had done so for the "good of mankind," and to benefit "their people." While they had received token incentives, all agreed that these had not been enough to ultimately motivate them to participate. However, if larger numbers of respondents are needed, they felt it absolutely necessary that an incentive structure be instituted, but with selective input from respondents.

Several individuals felt that their experiences in prior research had been somewhat disappointing for several reasons: 1) a lack of a personal 'touch' (being treated like a "number"); 2) a lack of questions specific to their situation (language far too complicated and not allowing for food and lifestyle choices specific to their lives); 3) a lack of explanation as to why their participation was important and relevant; 4) a lack of feedback about study progress and results; and 5) being treated disrespectfully. One respondent said, "If you treat me with respect I will do things for you . . . if I sense that you are looking down on me—don't bother me—don't bother asking me for help." Another respondent's exclamation reiterated the common theme of frustration at the paucity of Black investigators: "the reason I don't participate in these studies is because I don't like who's doing them . . . if it doesn't appeal to me then what they're doing it for is not important to me . . ."

Most respondents expressed greater comfort about participating in a survey than in research involving invasive procedures, especially phlebotomy and fat aspiration. If participation in the survey were linked to consent to such procedures, many asserted that this would discourage their overall involvement in the study. Several individuals commented on the lack of Black study personnel in the past, and were positively impressed by the presence of a "mixed" study team during the formative phase. Questions as to the overall ethnic composition of the research team arose and were met with cautious excitement when a commitment to meaningful and consistent involvement of Black personnel in all phases of the research was reported.

Remaining Barriers to Participation

All respondents were familiar with the Tuskegee Syphilis Study, and could recall other negative research conducted on Black subjects in the past. They felt that this history, along with negative personal experiences with the healthcare "system," decreased the likelihood of large numbers of Black Adventists participating in the future.

Most respondents indicated that the length of the questionnaire and the anticipated time involved in presenting for phlebotomy or fat aspiration were major barriers. For instance, issues such as having a second job, being a single head of household, and lacking a regular and stable income, were mentioned as barriers for follow-through, even among individuals with good intentions. In addition, sub-optimal reading levels and fatigue were identified as barriers. The instrument was seen as intimidating, and respondents felt that it would become increasingly unlikely for respondents to finish the questionnaire if they had to complete it in several sittings.

Another important barrier identified was the respondents' concern about confidentiality. The request for one's social security number and other identifying information, especially, were seen as intrusive and raised concerns as to what would be done with their information and specimens. In addition, participants voiced concern regarding the true intent of providing informed consent. Some saw it as potentially relinquishing or "signing away my rights."

Facilitators of Participation

Despite the concerns expressed, a sense of pride and co-ownership for a health study of national significance emerged, and participating in its development was characterized as empowering. Respondents indicated that particular value would be ascribed if their religiously inspired healthy lifestyle could be shown to be protective and useful to African Americans as a group. Many respondents were interested in knowing more about the real life implications of certain risk and protective behaviors in the prevention of diseases with high prevalence rates in the Black community.

More persistent recruitment efforts, which acknowledge the shortcomings of the past and demonstrate sensitivity to the present needs and special circumstances of Black Americans (in general), and within the church (specifically), were identified as an overarching approach to overcoming past obstacles. Consulting the church 'community' about the study, and integrating community members into the study in meaningful ways, was viewed as a critical element of this process. In addition, most respondents agreed that better marketing of the study via an explanation of the benefits of the study to Blacks, as well as providing follow-up study updates, were necessary to motivate participation. Having the data collected by "people like us," to whom they can relate, and who speak their language, was seen as "a must."

Role and Meaning of Incentives

All respondents agreed that prior study incentives (measuring tapes, inscribed refrigerator magnets, pens and pencils) were inadequate compensation for their time and effort. However, incentives were seen as necessary and motivating because they acknowledge respondent burden. Many indicated that personal monetary incentives, however small, would motivate them more than a larger contribution to the church for operational expenses, since the latter was too "abstract" and removed from their own sphere of influence. With respect to the amount necessary to make the incentive meaningful, most agreed that it needed to be more than a "couple of dollars," and that $10–15 would be seen as a sufficient gesture. Further, most felt that this incentive needed to be given in the form of a check or cash, rather than as a coupon for "goods."

Most respondents agreed that each church needed its own personalized approach, as churches varied greatly with respect to their membership composition. There were, however a number of suggested commonalities:

1. Two key roles must be filled in getting church members successfully engaged and motivated. First, the importance of buy-in by the local pastor was stressed. Second, the availability of paid part-time assistance by a member of the congregation was seen as necessary in organizing the church around data collection issues. Respondents agreed that most members would not "enroll" in the study without the a personal "touch" of having known individuals in key positions, rather than these roles being played by "outsiders." In addition, this would convey study investment in, and commitment to, mutual benefit by allowing some church members to supplement their income in ways that build capacity within the church. A system was suggested in which the pastor would give a motivational sermon and the part-time assistant(s) would provide reminder notices/health testimonies about the study during the announcement period of the main church service for a number of weeks prior to actual data collection. These activities would then culminate in a group meeting,

linked to a potluck, and a musical program, organized for the sole purpose of completing a "chunk" of the survey in a large group. High school youth fulfilling community service requirements, and retired seniors, were identified as likely volunteer pools from which to augment paid assistants. In addition to staffing these group sessions, paid assistant(s) and volunteers would remind and aid enrollees on a one-to-one basis. Since few can complete the survey in one sitting (certain parts require consulting one's kitchen and medicine cabinets), the enrollment card and consent form should be completed first. The paid assistant(s) and volunteers would collect and mail these to the study headquarters, allowing study investigators to follow up by telephone with the members who started the questionnaire, but did not complete or return it.

2. Culturally tailored, attractive study marketing materials must support recruitment efforts. Pamphlets or brochures, written in simple and culturally appropriate language, would summarize the main points made during the sermon and announcements. The respondents agreed that care needed to be taken to avoid too much didactic content, as overtaxed members would likely scan, rather than read, lengthy diatribes. Disclosure of unpopular procedures (eg, phlebotomy) to which members may be asked to submit, and an explanation of confidentiality protections should be included. These materials would be used as inserts in the weekly church bulletin, and displayed in church lobbies. In addition, a large appealing poster could be hung in prominent places in church lobbies to remind members of the study's importance.

3. The study investigator outreach team must be culturally sensitive and competent. Those who train church member assistants and participate in study marketing efforts must be culturally sensitive and competent Black professionals, aware of, and respectful toward, the history and idiosyncrasies of Adventist culture.

4. Regular updates on progress and results should be provided throughout the study. Visual aids, such as a church enrollment goal barometer, were suggested (similar to displays used for church building campaign contributions, for instance). In addition, relevant study-derived data should be shared as soon as possible.

DISCUSSION

The findings of this study with regard to barriers to, and facilitators of, research participation among Blacks, mirror those of other investigations: mistrust of, and fear of exploitation by, White researchers; little perceived benefit derived from participation; and experiences of disrespectful treatment by White institutions, particularly in health care (eg, Swanson and Ward[5]; Allen[42]; Shavers et al[20]). Many, though not all, of the recruitment strategies suggested by respondents in this study have been employed in some form in other recent church-based studies, the overwhelming majority of which are intervention, rather than observational, research (eg, Yanek et al[43]). The observational nature of the AHS-2, therefore, presents particular challenges to the engagement of the Black community, given the recurrent theme of past exploitation (eg, that researchers gain access, collect data, expose disparately high rates of life-threatening conditions, and then depart, packing their "stuff" without offering any plausible solutions for lowering risks, or improving health outcomes). Critical to the success of this and future efforts is the demonstration and communication of the potential for *real* mutual benefit at the outset; respectful and culturally proficient treatment of participants; and on-going sharing of results, in a way that highlights and credits Black participation at every level of the study. An important limitation of this study is its small convenience sample: data from this group cannot be generalized even to all Black Adventists, much less all Black church members, or community members. Nonetheless, the recurrence of themes surfacing in similar qualitative studies of Blacks in other settings attests to the universality of many of the findings for this socioeconomically marginalized group.

Adventist Health Study-2 (AHS-2) recruitment strategies reflect the input of this study. First, part-time assistants who are members of each congregation are compensated as study coordinators to extend the "reach" of the motivational sermons and announcements by pastors reading them during church services, and to provide personalized attention for congregants needing assistance in completing the lengthy questionnaires. Second, marketing materials (brochures, fact sheet inserts in existing Adventist publications, videos) have been designed specifically: 1) to streamline and target factual content to Blacks, eg, "For Black Adventists, the risk of dying is . . . 30% higher in non-vegetarians [than vegetarians], 40% lower in those eating nuts 5 times a week;" 2) to incorporate culturally relevant icons and role model images such as the Oakwood College logo (the only historically Black Adventist college), and photos with quotations motivating participation from leaders within the Black Adventist community; and 3) to invoke themes that resonate for Blacks,[35] eg, "Our tax dollars are supporting this research, but only by participating in large numbers will we as Black Americans benefit." Third, cultural proficiency is infused in several ways: 1) convening of an advisory committee comprising predominantly Black academics and professionals with relevant expertise for annual in-person meetings with ad hoc teleconference follow-up to recommend strategies and suggest solutions to difficulties encountered; 2) pursuing efforts to bridge historical schisms with Oakwood College, and to create a substantive partnering relationship, eg, seeking a NIH Minority Supplement Award to the study for

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a junior investigator on Oakwood's faculty (also an advisory committee member), exploring the creation of a study recruitment project involving Oakwood College students and providing them with research exposure and experience; and 3) a researcher with extensive experience in recruiting and retaining Blacks in public health research and service efforts (AKY) was hired as a co-investigator/consultant. Finally, study data are shared with congregants through articles in existing Adventist publications, through the creation and distribution of an annual newsletter, "A Legacy for Life," by providing fact sheets to participating pastors and congregation study coordinators for word-of-mouth dissemination, and by placing planned editorial submissions to and paid advertisements in Black newspapers.

The results of this qualitative study reinforce the importance of the careful cultural tailoring of recruitment and retention strategies to accommodate and embrace inter-ethnic *and* intra-ethnic variations, as "culture" is also determined by gender, level of formal education, income, religious beliefs/participation, wealth, national origin, US region of residence, sexual orientation, health/disability status, and other socio-demographic characteristics. If we are to decrease health disparities among minority populations in the United States,[31,44] we must find plausible solutions for dealing with the "trust" element, which, in essence, is the central barrier to research participation. Gaining the trust of this racial/ethnic population of Americans is possible, but only incrementally, a few positive research experiences at a time. Recruitment and retention successes are increasingly reported.[35,39,45–49] For example, one study on hypertension in a large cohort of Blacks reported, "that large numbers of African Americans can be recruited in large, collaborative clinical trials."[36] As was the case in similar efforts with positive outcomes, these researchers attributed their success to an ethnically diverse research staff and a culturally sensitive approach to recruitment. However, fundamental systemic changes are required to adapt the research paradigm, particularly in the area of social and behavioral research, to a multicultural, inclusive model.[50] Should we elect to meet this challenge immediately and aggressively, widening disparities in health outcomes will be prevented, with further movement toward the American ideal of equality of opportunity.

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