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Recruitment of Minority and Underserved Populations in the United States: The Centers for Population Health & Health Disparities Experience

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Abstract

Objective—The recruitment of minority and underserved individuals to research studies is often problematic. The purpose of this study was to describe the recruitment experiences of projects that actively recruited minority and underserved populations as part of The Centers for Population Health and Health Disparities (CPHHD) initiative.

Methods—Principal investigators and research staff from 17 research projects at eight institutions across the United States were surveyed about their recruitment experiences. Investigators reported the study purpose and design, recruitment methods employed, recruitment progress, problems or challenges to recruitment, strategies used to address these problems, and difficulties resulting from Institutional Review Board (IRB) or Health Insurance Portability and Accountability Act of 1996 (HIPAA) requirements. Additionally, information was collected about participant burden and compensation. Burden was classified on a three-level scale. Recruitment results were reported as of March 31, 2007.

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Results—Recruitment attainment ranged from 52% to 184% of the participant recruitment goals. Commonly reported recruitment problems included administrative issues, and difficulties with establishing community partnerships and contacting potential participants. Long study questionnaires, extended follow-up, and narrow eligibility criteria were also problematic. The majority of projects reported difficulties with IRB approvals, though few reported issues related to HIPAA requirements. Attempted solutions to recruitment problems varied across Centers and included using multiple recruitment sites and sources and culturally appropriate invitations to participate. Participant burden and compensation varied widely across the projects, however, accrual appeared to be inversely associated with the amount of participant burden for each project.

Conclusion—Recruitment of minority and underserved populations to clinical trials is necessary to increase study generalizbility and reduce health disparities. Our results demonstrate the importance of flexible study designs which allow adaptation to recruitment challenges. These experiences also highlight the importance of involving community members and reducing participant burden to achieve success in recruiting individuals from minority and underserved populations.

Keywords

health disparities; recruitment; underserved populations; minorities; participant burden

Introduction

One of the regrettable hallmarks of the U.S. healthcare system is that substantial health disparities exist among population subgroups. Examples include the higher breast cancer mortality among African American women compared to Caucasian women [1], increased prevalence of diabetes among African Americans, Hispanics, and Native Americans [2,3], and lower use of preventive screening among rural populations [4,5]. Narrowing the often wide gaps in health among segments of the U.S. population will involve substantial research into the causes of these disparities and ways of preventing them.

Research intended to address health disparities requires adequate representation of those most affected by the disparities. Participating in research may decrease health disparities by giving the traditionally underserved access to the newest treatments and technologies available only through clinical trials [6,7] and by improving the generalizability of trial results to minority and underserved populations [8–10]. Recruitment of minority populations, however, has proven to be a substantial challenge for investigators. Barriers have been identified at the patient, provider, system, and community level, and include mistrust of medical research [11–24], lack of awareness of available studies [12,17,20,21,25–28], economic burden [6,12, 16,28–32], and failure to meet eligibility criteria [33–35].

Suggestions have been made for frameworks that conceptualize and aid in the design of the recruitment process in order to effectively recruit members of underserved populations. Brown et al. [36] suggested that willingness to participate in research is determined by “awareness, acceptability, and access;” therefore, activities focused on education, generating social support from community leaders, and removing access barriers should result in improved recruitment of minorities. Paskett et al. proposed the Accrual to Clinical Trials (ACT) framework that focuses on identifying and addressing barriers at participant, provider, system, and community levels [20]. Another conceptual framework by Brown and Topcu proposes that participation is influenced first by an individual’s desire to enroll and then by factors including their personal beliefs about the disease, past experiences with the healthcare system, and social support for their participation in the trial [37].

Common to all the proposed frameworks is the notion that the decision to participate is not influenced by individual-level factors alone, and that the characteristics and beliefs of others,

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including healthcare providers, the healthcare system, the community, and society affect an individual's decision to participate in the trial. Thus, these frameworks suggest that the relevant communities must be involved in planning the study [17,38–41], and to do this, understanding the culture and intracultural variation of the target community [42,43] and the history of the community's experience with the health care system [17] are important. If a study is to be successful in recruiting members of underserved and minority populations, strategies that involve all factors of the target population (i.e. "community") must be utilized to identify and address critical cultural factors.

The Centers for Population Health and Health Disparities (CPHHD) initiative, funded by the National Institutes of Health (NIH), focuses on identifying and addressing health disparities among a variety of minority and underserved populations. The Centers each use Community-Based Participatory Research (CBPR) methodology, a strategy that involves the community in every facet of the research, in at least one of their projects. The goal of this paper is to describe the recruitment experience of the Centers in this initiative through March 31, 2007 and to provide examples of strategies employed to aid in recruiting underserved populations to research studies.

Methods

A total of twenty-one research projects involving the active recruitment of participants from minority and underserved populations and conducted through the CPHHD initiative at eight institutions in the U.S. were identified and included in this review of recruitment strategies. The projects described were still actively recruiting, and results represent information collected through March 31, 2007. Principal investigators and research staff from each project provided information using a standardized data collection form about the study purpose and design, recruitment methods employed, recruitment progress as of March 31, 2007, problems or challenges to recruitment, and problems resulting from Institutional Review Board (IRB) or Health Insurance Portability and Accountability Act of 1996 (HIPAA) requirements. Information about how these problems were addressed was also solicited from the Centers. Investigators at The Ohio State University CPHHD pilot tested the data collection form used in this study. The results were compiled and inspected for commonalities in the Centers' experiences, and percentages were calculated to describe the frequency of the responses overall. Additionally, information describing participant burden and compensation for each participatory research project was obtained from each Center.

For four projects, recruitment occurred within another project at that center (e.g. the Boston Puerto Rican Center on Population Health and Health Disparities consisted of four separate projects, but only one overall instance of active recruitment). Thus, there were only 17 projects that implemented active recruitment strategies. Percentages were calculated using the total number of active recruitment instances (n=17) as the denominator. For simplicity, these instances of recruitments are referred to as "projects" in the reporting of results. Participant burden was categorized into three groups, high, medium, and low. High burden included tasks such as an extended follow-up and several medical tests, while medium burden included follow-up visits with minimal medical testing, such as a blood sample. Low participant burden was defined as participating in a one-time survey.

Following is a brief description of each Center and the project(s) included in this paper; this information is also summarized in Table 1. All projects were approved by their respective Institutional Review Boards.

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Center for Interdisciplinary Health Disparities Research, University of Chicago

The primary focus of the Center for Interdisciplinary Health Disparities Research at the University of Chicago was to study social, behavioral, and biological reasons for disparities in breast cancer between African American and Caucasian women. The Social Environment, Stress, and Health project was a community-based longitudinal study of African American women in Chicago with a new diagnosis of breast cancer. The purpose of this project was to study how factors related to the patients' community, social situation, behaviors, and biological characteristics relate to breast cancer. Study participants were age 18 or older, African American, and non-Hispanic Caucasian women and provided data through in-person interviews.

Those enrolled in the study were followed for a combined twelve months, and were interviewed twice over two non-consecutive days at baseline, six months, and twelve months. Furthermore, blood samples were collected from all participants, and subjects consented to have previously excised tumors examined. Compensation was $30 per interview, for a potential total compensation of up to $180.

The Boston Puerto Rican Center on Population Health and Health Disparities, Tufts and Northeastern Universities

The primary focus of this center was to examine nutritional, genetic, and psychosocial factors that contribute to poor health outcomes in a longitudinal cohort of Hispanic men and women. To address this goal, this center conducted four research projects, all focusing on Puerto Rican men and women aged 45–74. Project 1 was a 2-year, prospective cohort study that investigated temporal associations between psychosocial stressors and certain disease outcomes, specifically diabetes and hypertension. Project 2 was a qualitative sociological evaluation in a representative subset of the cohort population aimed at understanding contextual sources of stress and adaptive mechanisms of adjusting to this stress. Project 3 examined two separate cohort subsets through intervention studies to evaluate the effectiveness of vitamin supplementation, food coupons and nutrition education, and social support over a two-year span. Project 4 investigated the relationship between these stressors, chronic disease outcomes, and genetics. Among a cohort subset, gene variants were determined, and responses to the varying interventions were compared.

Participants for all projects had a total follow-up length of two years. Only two interviews, however, were conducted—one at baseline and one at the end of the two-year follow-up. Phone contact was maintained every six months to administer a life events inventory. A blood sample was also collected at baseline and at the two-year follow-up. No other medical tests were performed. Compensation was $50 for both the baseline and two-year follow-up interview for a potential total of up to $100.

Institute for Health Research and Policy Centers, University of Illinois at Chicago

The Institute for Health Research and Policy Centers at the University of Illinois at Chicago applied, primarily, the elements of the Berkman and Glass model [44,45] to address racial disparities surrounding the diagnosis, treatment, and prognosis of breast cancer through elements of multidisciplinary research and community-based partnerships. The Institute undertook four projects. Project 1: Neighborhood and Individual Effect on Stage at Diagnosis evaluated both individual and neighborhood effects on breast cancer stage at diagnosis. Additively; Project 2: Social Network Effects on Breast Cancer Prognosis evaluated the effect of social networks on breast cancer prognosis; Project 3: Breast Cancer Delay in Black, Hispanic and White Women addressed delay in breast cancer diagnosis and treatment among African American, Hispanic, and Caucasian women; and Project 4: Mediators of Ethnic Disparity in Breast Cancer Prognosis examined mediators and ethnic disparities in breast

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cancer prognosis. All four projects were cross-sectional studies and included African American, Hispanic, and Caucasian women aged 21–79. These multilevel projects were largely community-based, and focused on social, behavioral, and environmental issues.

Each project conducted at the University of Illinois at Chicago was a one-time, cross-sectional interview. Only Projects 1 and 4 collected a blood sample. Compensation for Projects 1 and 4 was, initially, $50 for the one-time interview. That amount, however, was increased for patients enrolled on or after February 1, 2007 to $100 for the baseline interview and an additional $50 for a blood sample. Projects 2 and 3 offered $25 for the completion of the survey, however, Project 2 stopped providing compensation for patients enrolled after January 31, 2007.

The Ohio State University Center for Population Health and Health Disparities

The Center for Population Health and Health Disparities at The Ohio State University (OSU) focused primarily on addressing the high rates of cervical cancer incidence and mortality in Appalachian Ohio. Partnering with the University of Michigan and using CBPR with the framework of the Social Determinants of Health model [44,45], the OSU Center conducted three projects under the title Community Awareness, Resources and Education (CARE). All three projects examined cervical cancer in women from all races and ethnicities aged 18 or older. Project 1 investigated multi-level risks associated with Pap smear utilization and consisted of two phases. The first phase was a cross-sectional study analyzing risk factors associated with cervical cancer incidence, while the second phase examined the effectiveness of a lay health educator intervention to increase Pap smear utilization through a quasi-experimental, randomized control trial. Similarly, Project 2 evaluated the effectiveness of a lay health educator intervention in promoting smoking cessation in a quasi-experimental trial. Project 3 was a case-control study that evaluated the contribution of human papilloma virus (HPV), controlling for multilevel behaviors, to the incidence of cervical abnormalities in Appalachian Ohio.

Participants in Phase 1 of Project 1 responded to a one-time eligibility interview, and compensation was $10. The second phase of Project 1 involved two in-person visits and two phone calls from a lay health advisor to deliver a Pap test intervention for those randomized to the intervention group—one of each at baseline and one of each at the end of a 12–14 month follow-up. Compensation was $10 for responding to the baseline interview and another $10 for completing the 12–14 month follow-up for a total potential compensation of up to $20.

Participants in Project 2 were followed for 12 months and completed a baseline interview and interviews at three, six, and 12 months. Additionally, a saliva sample was collected. Compensation was $10 for completion of the baseline and 12 month interviews, and $15 for completion of interviews at three and six months. Total potential compensation for Project 2 was $50. Those randomized to the intervention group also received up to six visits by a trained lay health advisor who delivered the smoking cessation intervention over an eight-week period.

Eligible participants in Project 3 were contacted at baseline and assessed a second time once they were selected for inclusion in the study. Participants provided a blood sample, a second cervical smear and an HPV test sample during a routine Pap test. Participants were compensated $10 for the baseline survey, and another $10 if and when the second assessment was completed.

RAND Corporation Center for Population Health and Health Disparities

The RAND Corporation Center for Population Health and Health Disparities primarily studied the impact of neighborhoods on overall health, and how neighborhoods diffuse effects to the individual. Through community research, RAND also aimed to improve public policy regarding population health. The study consisted of four projects, however, only the first project

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involved recruiting community participants and was considered in this analysis. RAND conducted a cross-sectional study that focused primarily on determining the role of parks in physical activity and overall health. The study targeted all ages, all races, and both males and females, and examined the impact of developing and renovating recreational facilities on physical activity and other health outcomes. Participants were interviewed only once, and no compensation was provided.

Center for Population Health and Health Disparities at the University of Pennsylvania

The Center for Population Health and Health Disparities at the University of Pennsylvania concentrated on studying, evaluating, and disseminating information related to the interaction of biological, psychological, social, and clinical factors surrounding racial differences in prostate cancer. The center conducted two separate projects to examine prostate cancer. The Biological and Behavioral Predictors of Prostate Cancer project was a case-control study that examined the biological and behavioral predictors of prostate cancer recurrence in African-American and white men aged 35–90. The Determinants of Ethnic Differences in Quality of Life Following a Prostate Cancer Diagnosis project examined the psychological, cultural, and environmental determinants of ethnic differences in quality of life following prostate cancer diagnosis in non-Hispanic African American and white men aged 18–80 through a prospective longitudinal, CBPR study that was conducted collaboratively with the Philadelphia Chapter of the National Black Leadership Initiative on Cancer.

The Biological and Behavioral Predictors of Prostate Cancer project involved a one-time interview. Though follow-up is ongoing, it was clinically based via medical records. Only a subset of patients provided a blood sample. No other medical tests were required and no compensation was provided.

The Determinants of Ethnic Differences in Quality of Life Following a Prostate Cancer Diagnosis project followed participants for one year and involved four interviews, one at baseline and one at three, six, and 12 months. No blood samples were collected. To be eligible, however, men must have had a biopsy confirmed diagnosis of prostate cancer (though biopsy was not required for the study protocol). Compensation was $10 per interview for a potential total of up to $40 upon study completion.

University of Texas Medical Branch Center for Population Health and Health Disparities

The Center for Population Health and Health Disparities at the University of Texas Medical Branch (UTMB) managed two separate projects. The Environmental Risk, Coping, and Mexican Health Project, was a cross-sectional community study that examined the impact of environmental risk on health outcomes. This project enrolled both men and women aged 25 or older of all races, and involved a community-based, cross-sectional survey with subsequent follow-up interviews. The Liberty County Community-based Cancer Control Project, was a community-based longitudinal study that focused mainly on cancer incidence and prevalence in neighborhoods experiencing an influx of Hispanics. This project furthered the UTMB Center's overall focus on the phenomenon of overall lower cancer incidence and prevalence, lower prevalence of overall disease, and lower associated mortality in neighborhoods that experience Hispanic immigration. This project enrolled both men and women of all races and ages in an attempt to understand this protective effect which has become known as the "Hispanic Paradox."

The Environmental Risk, Coping, and Mexican Health Project followed participants for approximately five months. Investigators interviewed participants at baseline and at the end of follow-up. Participants provided a blood sample at the baseline interview. Additionally, height, weight, and blood pressure measurements were taken at baseline and at follow-up.

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Compensation was $15 for the baseline interview, $30 for providing a blood sample, and $15 for completing the follow-up questionnaire. Total potential compensation for participation was up to $60.

The Liberty County Community-based Cancer Control Project was a one-time, cross-sectional study. No biological samples were taken, though the project encouraged the community to increase screening adherence to mammograms and prostate-specific antigen (PSA) tests. No compensation was provided.

Wayne State University Center of Urban and African American Health

The Wayne State University Center of Urban and African American Health focused research efforts on understanding how the environmental, individual, biological, and genetic mechanisms operating in the surrounding Detroit community affect chronic disease conditions and their precursors. The Center conducted three individual projects.

The Exploring Changes in Experiences and Lifestyles (EXCEL) project was a randomized controlled trial that focused on African-American women aged 18–70 and the effects of lifestyle factors on breast cancer outcomes. This project was a 52 week study that conducted a baseline interview and interviews at three, six, and 12 months. A blood sample and Dual X-Ray were required. Participants received $15 and a $5 parking voucher per office visit. Total potential compensation was up to $100.

The Obesity, Nitric Oxide, Oxidative Stress and Salt Sensitivity Study (ONOSS) was a randomized controlled trial of African-American men and women aged 45 or older aimed at studying the effects of obesity, nitric oxide, oxidative stress, and salt sensitivity on cardiovascular disease risk. The project was a 78 week study and involved a baseline interview and interviews at three, six, 12, and 18 months. A blood sample was required of participants, as well as a Dual X-Ray, a gastric lavage, and an exercise test. Compensation was $40 each for the baseline interview and interviews at 12 and 18 months, plus an additional $80 dollars at each time point (baseline, 12 and 18 months) if a lavage was conducted. Compensation for interviews completed at three and six months was $15 each. A $5 parking voucher was also provided for each interview. Total potential compensation for participation was up to $415.

The final project, the Women's Healthy Lifestyle Study (WHLS) was a randomized controlled trial that explored the effects of changes in experiences and lifestyle on cardiovascular disease. WHLS targeted African-American women aged 18 or older. The project was a 33 week study and involved 16 clinic visits and 17 phone calls. Participants provided a blood sample and consented to a Dual X-Ray, absorbitiometry and SphygmoCor® measurements, and ambulatory blood pressure management. Participants were compensated $15 per office visit and given a $5 parking voucher. Total potential compensation was up to $320.

Results

The CPHHD projects varied in both disease and population focus, as previously described. The total number of participants to be recruited varied substantially among projects, as well (Table 2), ranging from 100 for the Women's Healthy Lifestyle Study at Wayne State University to a maximum of 2,400 for three different projects among different Centers. The median number of participants to be recruited among all included projects was 500, and more than one-quarter of the projects sought to recruit at least 1,000 participants.

Recruitment Methods

The CPHHD studies recruited participants using a variety of sites, sources and invitation procedures (Table 3). Most of the projects used multiple sites when recruiting participants,

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with 58.8% of the projects using at least two referral sites and 11.8% using at least three. The most common referral sites were community and hospital clinics. Nine of the seventeen projects reported using community clinics as a referral site for their participants. Similarly, hospital clinics were also important for recruitment, with six projects recruiting participants from patients seen in hospital clinics. Other common referral sources were community outreach (five), cancer registries (four), and hospital records (three). Less common referral sites were from another ongoing study (two), public records (two), random sampling of individuals through a multistage cluster design (two), parks and households (one), churches (one), and civic events (one).

Most projects also used multiple sources for referrals of potentially eligible participants. The majority of projects (82.3%) used at least two referral sources, while two projects reported using four referral sources. Ten projects (58.8%) reported using self-referral by potential participants (i.e. participants responded to a brochure, flyer, or other type of community posting). Research staff and clinic personnel were also important, with seven and five projects utilizing these sources, respectively. Six projects also reported using hospital or medical records as a referral source. Other less commonly used sources were from another ongoing study (two), location in the randomly selected census block (two), mass media (two), community coalitions (one), and cardiac rehabilitation programs (one).

Slightly over half (52.9%, nine) of the projects used only a single method of inviting potentially eligible participants to join their study, while six studies reported using two forms of invitations, and two studies reported using three. All but one of the projects (94.1%) reported using an in-person invitation procedure; that is participants were invited to participate through face-to-face encounters with clinic and/or research staff. Centers also commonly reported using mailed invitations either with (four) or without (four) telephone follow-up to invite potentially eligible subjects.

Recruitment Results

The total recruitment goal, accrual goal for recruitment through March 31, 2007, and the actual number recruited through that same date were reported for each project (Table 2). Fourteen of the seventeen (82.4%) projects with stated accrual goals for March 31, 2007 had achieved at least 75% of goal by this date. Recruitment to the March 31, 2007 goal ranged from 52.3% (158 recruited with a goal of 302) for phase 2 of project 1 at The Ohio State University to 184.0% (1,380 recruited with a goal of 750) for the Biological and Behavioral Predictors of Prostate Cancer Project at the University of Pennsylvania. Overall, six of the seventeen projects (35.3%) met or exceeded their accrual goal for the end of March, 2007.

In those studies desiring to recruit a multi-racial/ethnic population and reporting specific accrual results for each race/ethnicity, no clear pattern in terms of recruitment success was observed. For example, the Biological and Behavioral Predictors of Prostate Cancer Project at the University of Pennsylvania reported recruiting 1,149 Caucasian participants, more than two times their March 31, 2007 accrual goal of 500; yet they had recruited only 200 African American participants, eighty percent of their March 31, 2007 accrual goal of 250. Likewise, the Environmental Risk, Coping and Mexican Health Study at UTMB experienced somewhat greater success in recruiting non-Hispanics (1,297 to a March 31, 2007 accrual goal of 800 (162.1%)) than in recruiting Hispanics (1,458 to a March 31, 2007 accrual goal of 1,600 (91.1%)). Conversely, projects 1 and 4 at the University of Illinois at Chicago reported greater success in recruiting minorities (297 African Americans to a March 31, 2007 goal of 270 (110.0%), and 78 Hispanics to a March 31, 2007 goal of 96 (81.3%)) than they did in recruiting Caucasian participants (185 to a March 31, 2007 goal of 270 (68.5%)).

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Recruitment Problems and Challenges

The projects reported a wide variety of problems and challenges encountered during recruitment (Table 4). One of the most common types of problems reported was related to the coordination with clinics used for recruitment; 52.9% of the projects reported at least one problem in this category. Coordination problems with clinics included difficulty in identifying a clinic willing to participate in recruitment, as well as coordination with the clinic's administration. Investigators noted that the clinic staff was already busy and lacked the staffing requirements necessary for adequate recruitment and for carrying out study activities. Further, one project reported that physicians and staff often did not make study recruitment a priority in their daily activities. Recruitment was also hindered by the lack of space available to research staff in the clinics, making on-site interviewing of potential participants difficult. Finally, one project also noted that the clinic restricted the research staff's access to the charts of potentially eligible patients.

Other common challenges to recruitment were related to administrative issues. Over half of all projects (58.8%) reported at least one problem/challenge that fell into this category. Projects reported poor cooperation from local hospitals and physicians as well as poor communication between researchers and clinic personnel. One Center reported significant difficulty in acquiring their state cancer registry data which were to be used for recruitment because of difficulties encountered in trying to obtain a contract with the state health department. Another project reported problems in establishing partnerships within the communities they were targeting for recruitment. Staffing problems were also commonly reported, including difficulties in managing research staff working away from the university and not having enough personnel to adequately manage recruitment.

Many projects (47.6%) also reported problems with eligible participants who refused to respond, failed to show up for scheduled appointments, or disregarded follow-up attempts made by mail and/or telephone. Further, many individuals were reportedly either unwilling to participate or were initially willing but later changed their minds. When participants did schedule clinic appointments, these were frequently cancelled. Investigators also reported difficulty in locating potential participants, due to the targeted population being either highly transient or spread across a large geographic area. One Center also reported that potential participants were mistrustful of research and lacked an understanding about the potential benefits of research to their community.

Characteristics of the projects themselves also presented challenges to recruitment. Two Centers reported that completion of a lengthy study questionnaire was a barrier to recruitment, while another reported that the long duration of follow-up was a barrier. Problems with the eligibility criteria were also reported, including criteria that were too narrow and inconsistent with the culture of the target population, exclusion of many participants due to high body mass index (BMI), and simply having a lower rate of eligible individuals than initially estimated. Two Centers reported that the timing of their recruitment was shortly after diagnosis or surgery for the condition under study, causing a burden for potential participants, and hindering recruitment. Other commonly reported problems were related to the busy schedules of potential participants and the limited time available for participant recruitment. UTMB's Environmental Risk, Coping and Mexican Health Study experienced extremely unique problems related to the occurrence of local disasters, including an explosion at a nearby chemical plant and the landfall of Hurricane Katrina.

Recruitment problems related to IRB and HIPAA

Ten of the projects (58.8%) reported problems related to IRB approval or restrictions (Table 5), with the time required to obtain IRB approval being the most common problem reported.

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Both the time needed for preparation of the IRB application and the time needed to obtain approval were often longer than anticipated, leading to delays in beginning recruitment. Projects also reported that their IRBs were overburdened and restricted the number of amendments that could be submitted at one time. Other problems included needing additional certificates of confidentiality or consents, difficulties in coordinating IRB approval at multiple institutions, and problems related to the use of non-university affiliated clinics and clinic staff for recruitment.

Only three Centers reported having recruitment problems related to HIPAA requirements (Table 5). The projects at OSU reported difficulty due to differing interpretations of HIPAA by the researchers and staff at each participating clinic, as well as restrictions from HIPAA that would only allow contact with clinic patients through clinic staff. UTMB's Liberty County Community-based Cancer Control Project experienced similar challenges due to HIPAA restrictions that disallowed direct contact of participants by the research staff, and required adherence to strict privacy guidelines to prevent even perceived breaches of privacy. One project at the University of Pennsylvania also reported HIPAA-related problems, specifically that recruitment was prevented due to lack of private space in which to interview patients.

Attempted Solutions to Identified Recruitment Problems and Challenges

Efforts to address recruitment problems were as diverse as the problems themselves (Table 4) and focused on issues at the different levels described in the ACT framework[20]. The most common attempted solution was community outreach, with 71.4% of all projects reporting at least one solution in this category. Attempts at community outreach included establishing partnerships with community representatives and organizations, soliciting help from a previously established community advisory board, holding meetings with cancer registrars and physicians, sponsoring frequent, in-depth presentations to groups of potentially eligible individuals, emphasizing the benefits of the research to the community, and providing incentives and personalized recruitment materials.

Protocol changes in response to recruitment difficulties were also commonly employed (eight projects). In some cases the eligibility criteria or recruitment goals were revised, while in other cases the timing of enrollment or the length of the study was modified. Modifications were also made to recruitment procedures, including extending study area boundaries, implementing on-site recruitment, and establishing a toll-free number to encourage follow-up from participants. Other protocol changes included offering extra assurances of confidentiality, changing the questionnaire content or the timing of administration, and providing gift certificates as incentives for participation.

Changes to study management were implemented by nine projects in response to recruitment challenges. Such changes included developing computerized data tracking and reminder systems. One project retrained their interviewers in how to present the study to potential participants, while others increased their personnel effort devoted to recruitment. Multiple projects increased the number and frequency of meetings held with key players in recruitment, including providing updates to clinics about recruitment at their site. Other efforts to address recruitment problems included enlisting the help of additional physicians or hospitals, and hiring additional personnel to support recruitment efforts. Some projects also extended their work hours and provided home visits to accommodate the busy schedules of potential participants. UTMB's Environmental Risk, Coping and Mexican American Health Study addressed their disaster-related problems by delaying their scheduled interviews while the community dealt with the plant explosion and by ensuring the security of their data during Hurricane Katrina.

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Participant Burden and Compensation

Seven (41.2%) of the projects that actively recruited participants had a medium participant burden. Six (35.3%) had low participant burden, and only four (23.5%) projects had high participant burden. None of the projects with high participant burden reached their March 31, 2007 accrual goal, while 28.6% of projects with medium burden and 66.7% of projects with low participant burden reached their March 31, 2007 accrual goals. Median total potential compensation for projects with high, medium, and low participant burden was $250, $50, and zero dollars, respectively. Most projects (nine, 52.9%) provided participants with some compensation but less than $100. Four projects (23.5%), all with low participant burden, provided no compensation, and four projects (23.5%), all with high participant burden, provided compensation in excess of $100. These results are summarized in Table 6.

Discussion

The Centers for Population Health and Health Disparities initiative focuses on understanding and addressing various health disparities in different populations that suffer a disproportionate disease burden. This report summarizes both the recruitment issues surrounding minority and underserved populations served by the CPHHD and the efforts made to address these emerging recruitment problems. Consistent with previous research, strategies for reaching recruitment goals used by almost all of the Centers were similar to those suggested in the ACT framework [20]. These strategies include using multiple recruitment sites and sources, using members of the target population in planning efforts, educating the population about the importance of the study, improving staff sensitivity, providing personal, culturally appropriate invitations to participate in studies, and providing either compensation or benefit to community members for their participation [20,46]. By using a recruitment framework, effective strategies may be incorporated at multiple levels (individual, provider, healthcare system, community) to improve recruitment. The rate of recruitment as of March 31, 2007 varied from 52% to 184% of the recruitment goals for that date, though some sites reported either much lower or much higher recruitment of underserved and minority populations.

Common problems and challenges to recruitment were reported, with the most prevalent problem being related to the clinics where participants were being recruited. Specifically, researchers experienced difficulty working with clinic staff and physicians to implement recruitment procedures. These findings suggest that although many research studies rely on physicians to refer potentially eligible patients, physicians themselves can act as barriers to recruitment. Many physicians lack awareness of ongoing research projects [18,20,47,48], worry that they will lose control over their patients' medical care and damage the doctor-patient relationship by referring patients to a study [6,18,20,48,49], believe research activities would take up too much of their time [12,16,49], and view clinical trials as complex and providing care that is inferior to standard treatment [48]. Specific to minority recruitment, physician-level barriers further include having few minority patients in their practices [50], and perceptions that minority patients are less likely to want to participate in research [51].

Other common problems included administrative issues, forming partnerships with communities, staffing changes, and difficulties contacting potential participants. Characteristics of the research studies themselves also posed recruitment problems including long questionnaires, long follow-up duration, and narrow eligibility criteria. Notably, the recruitment rate appeared to vary by the amount of participant burden for each project, while compensation seemed to have little impact on the rate of recruitment. While this study was unable to test this empirically, future studies should directly examine the relationship between the level of burden placed on participants and their corresponding likelihood of study participation and overall rate of accrual. The majority of projects reported difficulties with IRB

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approvals that caused delays in starting recruitment. Conversely, HIPAA requirements did not negatively impact most of the projects.

As part of the CPHHD initiative, efforts to address recruitment problems included community outreach, amending the study protocol, and modifying recruitment procedures, questionnaires, and management strategies. These strategies were implemented individually by some Centers, and either incrementally or concurrently by other Centers. Some of these same strategies have resulted in successful recruitment in previous studies [34,52–68].

As with any study, there are several limitations and strengths in summarizing the Centers' approach to participant recruitment. Limitations include difficulties comparing Centers with different study designs, variation in population size and the number recruited across the Centers, and the fact that the participants were recruited from sites that differed in both demographic makeup and geographic location. Additionally, Centers differed in their reporting methods, with some Centers reporting recruitment information for each research project and other Centers reporting information for the entire Center. Specifically, these limitations prevent us from explicitly determining what exact strategies worked in the context of CPHHD recruitment.

While this study examined accrual goal attainment percentages, implemented strategies were not specifically tested, either within or between Centers, because study designs and recruitment methods varied so dramatically across projects. Compounding this difficulty was the fact that recruitment plans themselves demand flexibility over time and in reality no control groups could have been established to compare attempted recruitment solutions. Thus, as described by Larkey et al., while many of the strategies implemented may have improved minority and underserved accrual to the projects, this analysis of the CPHHD Centers recruitment strategies cannot distinguish which recruitment efforts were most effective [69]. Furthermore, not meeting recruitment goals may be a function of varying research designs, rather than similar recruitment problems related to underserved and minority populations.

Although vast differences between the Centers can be considered limitations to a degree, they have also illuminated the immense diversity of the recruitment strategies occurring at the Centers. This study provides a broad overview of problems faced by investigators attempting to recruit minority and underserved populations in clinical research with the overall goal of reducing health disparities and increasing the generalizability of clinical trial results. Common problems associated with participant recruitment have emerged and served as a catalyst for the CPHHD investigators to be flexible in their strategies to meet the various study recruitment goals. The importance of being able to modify recruitment strategies after the study begins and adhere to community-based, multilevel frameworks, while maintaining scientific integrity is an important lesson learned by this evaluation of participant recruitment across the CPHHD centers. Finally, as with any study that attempts to actively recruit participants, careful attention should be paid to the amount of burden placed on and compensation provided to those participating in the research. Future studies should build upon these findings, and look beyond unique and similar challenges and attempted solutions to such challenges between varying minority and underserved recruitment efforts to examine the effectiveness of specific recruitment techniques. These observations must be considered in future research studies in order to make serious attempts to reduce health disparities.

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Table 1

Description of projects within each Center for Population Health and Health Disparities

	Principal Investigator	Study Design	Health Focus	Gender	Age Range	Race	Ethnicity
terdisciplinary Health Disparities Research, University of Chicago							
	Gehlert	Community-based longitudinal study	Breast cancer	Female	≥18	African-American and Caucasian	Non-Hispanic
uerto Rican Center on Population Health and Health Disparities. Tufts/Northeastern Universities							
	Tucker	Longitudinal Cohort	Stress, cognitive and physical function	Males and Females	45–74	Caucasian	Hispanic, Puerto Rican
	Falcon	Qualitative evaluation of representative subset	Stress and adaptive mechanisms	Males and Females	45–74	Caucasian	Hispanic, Puerto Rican
	Bermudez	Intervention on subset	Stress, nutrition, and vitamin supplementation	Males and Females	45–74	Caucasian	Hispanic, Puerto Rican
er	Ordova	Genetic analysis of cohort	Stress and Genetics	Males and Females	45–74	Caucasian	Hispanic, Puerto Rican
Health Research and Policy Center at University of Illinois at Chicago							
go:	Warnecke (Project 1) Rauscher (Project 4)	Cross-sectional Survey	Breast cancer	Males and Females	21–79	African-American and Caucasian	Both
go:	Youm	Cross-sectional Survey	Breast Cancer	Males and Females	≥18	All	Both
go:	Ferrans	Cross-sectional	Breast Cancer	Female	≥40	African American, Caucasian	Both
te University Center for Population Health and Health Disparities							
	Paskett	Cross-sectional	Cervical cancer	Female	≥18	All[a]	Both
ct	Paskett	Randomized controlled trial	Cervical cancer /Pap test	Female	≥18	All[a]	Both

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	Principal Investigator	Study Design	Health Focus	Gender	Age Range	Race	Ethnicity
t 2	Wewers	Randomized controlled trial	Cervical cancer/tobacco cessation	Female	≥18	All[a]	Both
t 3	Ruffin	Case control	Cervical cancer /HPV	Female	≥18	All[a]	Both
ration Center for Population Health and Health Disparities							
cal	Cohen	Cross-sectional	Physical activity	Males and Females	All	All	Both
pulation Health and Health Disparities at the University of Pennsylvania							
r	Rebbeck	Case control	Prostate cancer	Male	35–90	African-American and Caucasian	Non-Hispanic
of r	Hughes-Halbert	Community-based longitudinal study	Prostate cancer	Male	18–80	African-American and Caucasian	Non-Hispanic
Texas Medical Branch Center for Population Health and Health Disparities							
th	Goodwin	Community-based cross-sectional study	General health Outcomes	Males and Females	≥25	All	Both
t	Philips	Community-based longitudinal study	Cancer	Males and Females	All	All	Both
University Center of Urban and African American Health							
ad	Artinian	Randomized controlled trial	Cardiovascular disease	Males and Females	≥18	African-American	Non-Hispanic
ss	Flack	Randomized controlled trial	Cardiovascular disease	Males and Females	≥45	African-American	Non-Hispanic
ay y	Djuric	Randomized controlled trial	Cardiovascular disease	Female	18–70	African-American	Both

casian due to demographics of Appalachian Ohio

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Table 2

Description of recruitment goals and attainment through 3/31/07, by Center and project

Center and Study Names	Total Goal	Accrual Goal for March 31, 2007	Number Recruited through March 31, 2007
Center for Interdisciplinary Health Disparities Research, University of Chicago			
Social Environment, Stress and Health	230	100	75
The Boston Puerto Rican Center on Population Health and Health Disparities. Tufts/Northeastern Universities			
All Projects	1375	1375	1082
Institute for Health Research and Policy Centers at University of Illinois at Chicago			
Breast Cancer Care in Chicago: Project 1 & 4	1000: 425 Caucasian, 425 African American, and 150 Hispanic	636: 270 Caucasian, 270 African American, and 96 Hispanic	560: 185 Caucasian, 297 African American, and 78 Hispanic
Breast Cancer Care in Chicago: Project 2	2400	1526	1334
Breast Cancer Care in Chicago: Project 3	300	265	230
The Ohio State University Center for Population Health and Health Disparities			
Community Awareness, Resources and Education (CARE): Project 1, Phase 1	720	415	571
CARE: Project 1, Phase 2	430	302	158
CARE: Project 2	300	306	177
CARE: Project 3	1360: 340 cases, 1020 controls	564: 144 cases, 420 controls	753: 63 cases, 690 controls
RAND Corporation Center for Population Health and Health Disparities			
The Role Of Parks In Physical Activity And Health	16 parks with 150 participants per park	2400	2452
Center for Population Health and Health Disparities at the University of Pennsylvania			
Biological and Behavioral Predictors of Prostate Cancer	1000: 500 cases each for Caucasians and African Americans	750: 500 Caucasian, 250 African American	1380: 1149 Caucasian, 200 African American, and 196 Other
Determinants of Ethnic Differences In Quality Of Life Following A Prostate Cancer Diagnosis	260	215	196
University of Texas Medical Branch Center for Population Health and Health Disparities			
Environmental Risk, Coping and Mexican American Health Study	2400: 1600 Hispanics 800 non-Hispanics	2400: 1600 Hispanics 800 non-Hispanics	2755: 1458 Hispanics 1297 non-Hispanics
The Liberty County Community-based Cancer Control Project	500	500	500
Wayne State University Center of Urban and African American Health			
Exploring Changes in Experiences and Lifestyles (EXCEL)	400: 200 dyads	330: 165 dyads	300: 150 dyads
Obesity, Nitric Oxide, Oxidative Stress and Salt Sensitivity	135	120	69
Women Healthy Lifestyle Study (WHLS)	100	81	71

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Table 3

Description of recruitment strategies by Center and project

Center and Study Names	Referral Sites	Referral Source	Invitation Procedure
Center for Interdisciplinary Health Disparities Research, University of Chicago			
Social Environment, Stress and Health	Community clinic or health care Practice Community outreach or resources Hospital clinic	Clinic staff Self-referral from flyers/brochures	In-person
The Boston Puerto Rican Center on Population Health and Health Disparities. Tufts/Northeastern Universities			
All projects	Community outreach or resources Public records Two-stage cluster design using census blocks	Location in targeted blocks through door-to-door enumeration Self-referral from flyers/brochures	In-person
Institute for Health Research and Policy Centers at University of Illinois at Chicago			
Breast Cancer Care in Chicago, All projects	Project 1,2, 4: Rapid case ascertainment, Illinois State Cancer Registry Project 3: Clinic patients are recruited face-to-face	Research staff Self-referral from flyers/brochures	Projects 1,2,4: Mailed with telephone follow-up and in-person interviews with those who agree to participate Project 3: In-person
The Ohio State University Center for Population Health and Health Disparities			
Community Awareness, Resources and Education (CARE): Project 1, Phase 1	Community clinic or health care practice	Medical records	Mailed with telephone follow-up
CARE: Project 1, Phase 2	CARE Project 1, Phase 1 Community clinic or health care practice	CARE Project 1, Phase 1 Medical records	In-person Mailed with telephone follow-up
CARE: Project 2	CARE Project 1, Phase 1 Community clinic or health care practice	CARE Project 1, Phase 1 Medical records	In-person
CARE: Project 3	Community clinic or health care practice	Clinic staff Medical records	In-person
RAND Corporation Center for Population Health and Health Disparities			
The Role Of Parks In Physical Activity And Health	Parks and households	Not applicable	In-person
Center for Population Health and Health Disparities at the University of Pennsylvania			
Biological and Behavioral Predictors of Prostate Cancer	Hospital clinic Hospital records	Clinic staff Research staff	In-person
Determinants of Ethnic Differences In Quality Of Life Following A Prostate Cancer Diagnosis	Community clinic or health care practice Hospital clinic	Clinic staff Research staff Self-referral from flyers/brochures	In-person Mailed Self-referral
University of Texas Medical Branch Center for Population Health and Health Disparities			
Environmental Risk, Coping and Mexican American Health Study	Households	Location in targeted blocks through door-to-door enumeration Mass media campaigns (television and newspaper ads) Self-referral from flyers/brochures	Community events In-person
The Liberty County Community-based Cancer Control Project	Churches Civic events Community outreach or resources Hospital records Public records State cancer registry	Community coalition members Medical records Research staff Self-referral from flyers/brochures	Community events In-person Mailed

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Center and Study Names	Referral Sites	Referral Source	Invitation Procedure
Wayne State University Center of Urban and African American Health			
Exploring Changes in Experiences and Lifestyles (EXCEL)	Community clinic or health care practice Hospital clinic	Cardiac rehabilitation programs	In-person
Obesity, Nitric Oxide, Oxidative Stress and Salt Sensitivity	Community clinic or health care practice Community outreach or resources	Mass media campaigns (e.g., radio spots, billboards, mass mailing) Self-referral from flyers/brochures	In-person Mailed
Women Healthy Lifestyle Study (WHLS)	Community clinic or health care practice Community outreach or resources Hospital clinic Hospital records State cancer registry	Clinic staff Medical records Research staff Self-referral from flyers/brochures	In-person Mailed

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Table 4

Recruitment problems/challenges encountered and solutions to these problems/challenges by Center and project

Center and Study Names	Problems/Challenges	Solutions
Center for Interdisciplinary Health Disparities Research, University of Chicago		
Social Environment, Stress and Health	Timing of initial interview close to surgery while patients are recuperating Potential participants reside outside of study boundaries Failure to return phone calls	Waited to schedule interview until at least 1 month post-surgery Created flexible scheduling to accommodate participants Extended study recruitment boundaries Staff traveled to residences of potential participants and leave a note and contact information in a sealed envelope taped to the front door Enlisted local hospital to assist in recruitment
The Boston Puerto Rican Center on Population Health and Health Disparities. Tufts/Northeastern Universities		
All projects	Locating participants Participants cancel interview appointments	Made contact with local Hispanic organizations and community leaders Instituted media advertising campaign
Institute for Health Research and Policy Centers at University of Illinois at Chicago		
Breast Cancer Care in Chicago, All projects	Completing the questionnaire Resolving a final contract with Illinois State Cancer Registry Patients identified within 45 days of diagnosis but not sufficiently adjusted to agree to participate Poor cooperation from local hospitals and physicians	Held in-person meetings with hospital cancer committee registrars Sent letters to all cancer chair physicians to inform about study Enlisted lawyers from the state to contact the hospitals and explain that the law making cancer reportable allowed the state to request the data mandated by the legislation anytime it was needed. Non-compliant hospitals were fined and began to reinterpret their policies; all hospitals are now on board.
The Ohio State University Center for Population Health and Health Disparities		
Community Awareness, Resources and Education (CARE) Project, All Projects	Clinic staff too busy/short-staffed Clinics lack necessary equipment/personnel for specimen processing Coordination of IRB approvals for clinics HIPAA concerns Identifying rates of abnormal pap smears in the clinic Locating interested and eligible clinics Obtaining space in clinics to store study equipment Working with clinic administration Lack of understanding about research and benefits to community Mistrustful of healthcare and research Mobile/transient population Travel necessary due to large geographic area covered by project Busy schedules of interested participants Contacting potential participants during busy clinic schedule Difficult to reach potential participants via mail or phone Failure to return phone calls/mailings Fewer eligible participants than expected Participants cancel appointments Participants change their minds about participating Participants interact with multiple staff members throughout program Lower participation rates of smokers Management of off-site research staff Survey instrument length and complexity	Asked for input from community advisory board Conducted pilot study to assess feasibility, study procedures, abnormal Pap rate, and refusal rates Facilitated clinic contact with experts to address HIPAA concerns Hired research nurses to alleviate perceived clinic staff burden Implemented reminder system to check for current information Made contact with community representatives to help locate and enroll clinics Scheduled multiple in-depth meetings and presentations Developed intricate email-based notification and data tracking system Discontinued sending self-administered survey and consent form with interview confirmation letter prior to interview visit Emphasized benefit to future health of women in community Emphasized short time commitment of study Included recruitment incentives with initial mailings Instituted regular conference and individual calls with field staff Offered extra assurance of confidentiality Placed project awareness materials in clinic waiting rooms Searched for phone numbers and addresses using online white pages Created personalized letters from clinic staff Implemented 1–800 number for follow-up from participants Offered gift certificates as incentives Offered the option of a shorter baseline survey Study coordinator called hard to reach participants with permission of clinic Retrained interviewers in project presentation Revised recruitment procedures Revised recruitment goals

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Center and Study Names	Problems/Challenges	Solutions
RAND Corporation Center for Population Health and Health Disparities		
The role of parks in physical activity and health	Environmental factors: dogs, gangs, locked gates	None
Center for Population Health and Health Disparities at the University of Pennsylvania		
Biological and Behavioral Predictors of Prostate Cancer	Time constraints for patient recruitment No space in clinic for staff to interview patients	None
Determinants of ethnic differences in quality of life following a prostate cancer diagnosis	Clinic doctors and staff do not make recruitment a priority	Instituted on-site recruitment in clinics by study staff Provided regular updates to physicians and staff regarding recruitment from their site Held regular strategic meetings at sites with low recruitment
University of Texas Medical Branch Center for Population Health and Health Disparities		
Environmental Risk, Coping and Mexican American Health Study	Scheduling an interview Schedule a blood draw A tragic plant explosion occurred during the data collection stage Katrina Hurricane delayed data collection	Left a sticky note, on the door, indicating when the next day and time the interviewer will stop by and a phone number to schedule an interview Had nurses conduct home visits and set a clinic on Saturday mornings from 9–12 Ceased data collection for that day and continued normal interviewing the following day. Several rejects to interview sky – rocketed after the explosion. Developed and conducted a sub-study pre- and post-explosion Shipped all data to collaborating site in North Carolina. Project manager also carried the data (CD) to Houston, Texas and interviewers had their data backed up in a storage card.
The Liberty County Community-based Cancer Control Project	Project depends on prior two studies which are still pending Delayed work in one area to prevent contaminating ongoing work of a related project Budgetary reductions have delayed progress Time consuming and difficult to build partnerships with communities Reduction of available cancer screening services in study communities	Moved forward with first phase of project in area with other ongoing research project Worked with communities to identify alternative funding sources Engaged in special efforts to maintain the trust of the community following closure of local clinics Gathered data and developed presentations for advocacy with county policymakers Emphasized risk reduction education to align with priorities of community partners
Wayne State University Center of Urban and African American Health		
Exploring Changes in Experiences and Lifestyles (EXCEL)	Organization/structure of referring cardiac rehab centers Potential participants unwilling to participate Busy schedules of participants Inadequate recruitment personnel to cover all referral sites Eligibility criteria too narrow and not consistent with culture	Instituted regular meetings between cardiac rehabilitation center staff and research staff Reshaped organizational structure to accommodate potential participants Offered home visits and extended office hours to accommodate schedules of participants Increased personnel efforts to accommodate new recruitment sites Revised eligibility criteria so they were congruent with culture
Obesity, Nitric Oxide, Oxidative Stress and Salt Sensitivity	Study population recruited from non-traditional clinic sources Potential participants excluded by high BMI Time commitment of study (39 weeks)	Established partnerships with community organizations Decreased length of study to 33 weeks Extended office hours to accommodate schedules of participants
Women Healthy Lifestyle Study (WHLS)	Poor communication between institutional cancer center clinic staff and study specific research recruitment coordinator Limited access to potential cancer center charts to 2 days per week	Continued checking clinic schedules for potentially eligible subjects Increased time spent on evaluation of potential participants to 5 days per week Expanded screening efforts by obtaining SEER cancer registry lists for entire region rather than for only study hospital Implemented weekly presentations to cancer survivor groups within the region

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Table 5

Recruitment problems/challenges encountered as a result of IRB or HIPAA by Center and project

Center and Study Names	IRB Issues	HIPAA Issues
Center for Interdisciplinary Health Disparities Research, University of Chicago		
Social Environment, Stress and Health	Time needed for approval longer than anticipated	None
The Boston Puerto Rican Center on Population Health and Health Disparities. Tufts/Northeastern Universities		
All projects	Required certificate of confidentiality to ask about HIV status	None
Institute for Health Research and Policy Centers at University of Illinois at Chicago		
Breast Cancer Care in Chicago, All projects	Time consuming to prepare submissions and amendments Difficulty obtaining IRB approval for the pretest and then for change resulting from the pretest.	None; project is exempt at each site because cancer is a reportable disease and by law the Illinois State Cancer Registry can request the data required by the registry at any point.
The Ohio State University Center for Population Health and Health Disparities		
Community Awareness, Resources and Education (CARE) Project, All Projects	IRB overburdened Need for IRB approval from multiple institutions Needed to clarify definition of "engagement in research" by the clinics Not allowed to use clinic staff as recruiters Only allowed to submit one amendment at a time Slow approval of protocol and project materials Time needed for approval longer than anticipated	Different interpretations of HIPAA and research by clinics and their staff HIPAA restrictions allowed patient contact only through clinic staff
RAND Corporation Center for Population Health and Health Disparities		
The role of parks in physical activity and health	None	None
Center for Population Health and Health Disparities at the University of Pennsylvania		
Biological and Behavioral Predictors of Prostate Cancer	None	Lack of private space to talk with patients prevents recruitment in order to protect privacy
Determinants of ethnic differences in quality of life following a prostate cancer diagnosis	None	None
University of Texas Medical Branch Center for Population Health and Health Disparities		
Environmental Risk, Coping and Mexican American Health Study	None	None
The Liberty County Community-based Cancer Control Project	None	Unable to contact participants directly Adherence to strict guidelines to avoid perceptions of breach of privacy and subsequent complaints to institutional and government authorities
Wayne State University Center of Urban and African American Health		
Exploring Changes in Experiences and Lifestyles (EXCEL)	None	None
Obesity, Nitric Oxide, Oxidative Stress and Salt Sensitivity	Required separate genetic consent	None
Women Healthy Lifestyle Study (WHLS)	None	None

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Table 6

Burden, compensation, and percentage of March 31, 2007 accrual goal attained for CPHHD projects that actively recruited human participants

Center and Study Names	Participant Burden[a]	Total Potential Compensation[b]	Percentage of March 31, 2007 Accrual Goal Enrolled
Center for Interdisciplinary Health Disparities Research, University of Chicago			
Social Environment, Stress, and Health	High	180	75.0
The Boston Puerto Rican CPHHD, Tufts / Notheastern Universities			
All Projects	Medium	100	78.7
Institute for Health Research and Policy Centers, University of Illinois at Chicago			
Projects 1 & 4	Medium	150	88.1
Project 2	Low	0	87.4
Project 3	Low	25	86.8
The Ohio State University CPHHD			
CARE Project 1, Phase 1	Low	10	137.6
CARE Project 1, Phase 2	Medium	20	52.3
CARE Project 2	Medium	50	57.8
CARE Project 3	Medium	20	133.5
RAND Corporation CPHHD			
The Role of Parks in Physical Activity and Health	Low	0	102.2
CPHHD at the University of Pennsylvania			
Biological and Behavioral Predictors of Prostate Caner	Low	0	184.0
Determinants of Ethnic Differences in QoL Following a Prostate Cancer Diagnosis	Medium	40	91.2
University of Texas Medical Branch CPHHD			
Environmental Risk, Coping, and Mexican American Health Study	Medium	60	114.8
The Liberty County Community-based Cancer Control Project	Low	0	100.0
Wayne State University Center for Urban and African American Health			
Exploring Changes in Experiences and Lifestyle (EXCEL)	High	320	90.9
Obesity, Nitric Oxide, Oxidative Stress, and Salt Sensitivity (ONOSS)	High	415	57.5
Women Healthy Lifestyle Study (WHLS)	High	100	87.7

[a] Participant burden was categorized as, high, medium, or low. High burden included tasks such as an extended follow-up and several medical tests, while medium burden included follow-up visits with minimal medical testing, such as a blood sample. Low participant burden was defined as participating in a one-time survey.

[b] Total potential compensation is measured in 2007 U.S. dollars