Linking Education to Action: A Program to Increase Research Participation Among African American Women

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Abstract

Background: Underrepresentation of African American women as research participants contributes to health disparities. Contemporary studies have focused on clinical trial (CT) participation; epidemiologic and genetic studies utilizing medical records and/or biological samples have received less attention. In partnership with The Links, Incorporated (The Links), a national service organization of professional African American women, this study sought to examine attitudes regarding chart review (CR) studies, genetic studies/biobanking (GEN), and CTs; develop; and evaluate an online education-to-action program.

Methods: In phase 1, focus groups were convened with members of The Links to inform the content and format of the program. Phases 2 and 3 involved designing and evaluating the program, respectively.

Results: Thirty-four women across three focus groups shared attitudes and perceptions regarding research and provided guidance for program development. Subsequently, 244 women completed the program (77% response rate), including pre- and post-assessments. Participants indicating that they “definitely” or “probably” (responses combined) intend to participate in research increased from 36.5% to 69.3% (pre/post-program). Agreement with the statement “research in the U.S. is ethical” increased (52.9% to 74.4%) as did factual knowledge regarding each of the study types. There was a decrease in reporting “little or no understanding” of study types (Pre/Post: GEN: 66%/24.9%, CR: 62.9%/18.4%, CTs: 40.7%/15.5%). Pre-program, few were “very positive” about the study types (14.3% GEN, 15.0% CR, 28.6% CTs); post-program ratings increased and equalized (42.8% GEN, 43.0% CR, 42.5% CTs).

Conclusions: An online education-to-action program targeting professional African American women improved knowledge, perceptions of ethics, and intent to participate in biomedical research.

Keywords: African Americans, clinical trials, research participation, genetic research, ethics

Introduction

THERE IS A need to ensure that biomedical research going forward reflects the prevalence of disease in racial/ethnic populations relative to population demographics. Underrepresentation of African American women as research participants limits the ability to identify health disparities in this population as well as measure scientific progress toward ad-

ressing and reducing disparities. In the context of cancer, for example, African Americans bear the greatest overall burden, yet they compose less than 2% of clinical trial (CT) participants¹; notably, for breast cancer (the highest incident cancer for women), African American women experience higher mortality compared with non-Hispanic whites,² yet there is a growing racial disparity in enrollment in breast cancer treatment trials.³ Moreover, although recent examination of demographic data for

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trial participants for new drugs approved between 2013 and 2015 by the United States (U.S.) Food and Drug Administration showed appropriate representation of women when estimated disease prevalence by sex is considered, it did not show appropriate representation of African Americans/blacks.⁴

The body of literature addressing underrepresentation of African Americans and women as research participants has focused on CTs⁵⁻¹² and, furthermore, on recruitment and not retention.¹³ Attitudes of African Americans regarding other types of biomedical research, such as epidemiologic and genetic studies that use medical record information in conjunction with biological samples, have only more recently been explored and they show a general willingness to participate.¹⁴⁻¹⁷ Likewise, recent examination of the self-reported race/ethnicity of participants in selected U.S. biobanks showed representation of blacks similar to current population estimates (13%), suggesting that successful recruitment to biobanks can be achieved.¹⁸ However, studies continue to outline barriers to enrollment of African Americans¹⁹ as well as facilitators, including greater effort and time devoted by study coordinators, and investigator engagement with the community to ensure successful enrollment and participation among African Americans.^{20,21} As noted by Strissel,²² epidemiologic and genetic studies are essential for advances in cancer research, including development of effective targeted therapies for women and minorities, thus it is important to further investigate attitudinal barriers and knowledge gaps with an eye toward intervention. In particular, little is known about attitudes and knowledge of key aspects of epidemiologic and genetic studies, particularly among African American women who are themselves well positioned to participate in research as healthy volunteers and to encourage others; this study endeavored to fill this gap in the literature.

As part of an ongoing academic/community partnership between Mayo Clinic and The Links, Incorporated (The Links),²³ a national volunteer service organization of over 14,000 professional African American women, this study sought to (1) examine attitudes regarding participation in research involving access to medical records, genetic studies/biobank research, and CTs; (2) develop; and (3) evaluate a novel, targeted, online educational program addressing these three types of biomedical research. This study builds on prior survey results obtained at the 2012 National Assembly of The Links, which showed less favorable attitudes toward and willingness to participate in research involving the use of medical records and concerns regarding research ethics in the U.S.²⁴ This preliminary work with The Links, together with the aforementioned literature noting underrepresentation of African Americans (more broadly) in research, provided the impetus for a more in-depth examination of key concerns to build the content for an online program targeted to The Links membership regarding research participation. Ultimately, the goal of the work was to develop an online program that addressed concerns, provided factual information, and activated African American women to seek opportunities to contribute to medical research, with the longer-term goal of reaching a broader African American community through dissemination and education activities within the service component of The Links organization.

Materials and Methods

Membership of The Links is organized into four geographic areas representing the Central, Western, Eastern, and

Southern regions of the U.S.; each region is further organized into chapters. This study was conducted in collaboration with the Central Area of the organization, which has 69 chapters in 15 states. The study occurred in three phases. Phase 1 involved formative qualitative inquiry *via* three focus groups with the goal of obtaining information to inform the content and format of the web-based program. The focus groups were convened in June and August of 2015 and moderated by a member of the investigative team who is experienced in qualitative methodology and is also a member of The Links organization (K.P.W.). An invitation to participate in a focus group for the purpose of sharing thoughts about research participation was included in The Links Central Area Conference registration packet. The invitation included options for focus group session times and information noting that participation was on a first-come, first-served basis up to a maximum of 15 participants per focus group. The Links were asked to rank their top three preferred sessions. They received a confirmation email with the time and place to report by the research team.

Focus group sessions were audio-recorded, professionally transcribed, and verified for accuracy and completeness by two investigators (C.R.B. and J.L.R.). The moderator guide assessed attitudes and perceptions regarding genetic studies/biobanking (GEN), research involving access to medical records (chart review [CR]), and CTs. Additionally, women were asked to openly reflect on a specific finding from the survey study: 52% of members of The Links who responded to the prior survey agreed with the statement 'Research conducted in the U.S. is ethical.' Finally, the desired format and features of a future web-based program were also queried in the focus groups to guide programming and design elements. Focus group participants received \$25 and a publisher's reprint of the article, which presented results from the survey conducted at The Links 2012 National Assembly.²⁴

Methods of directed content analysis were used to analyze the focus group transcripts.²⁵ Three members of the study team (C.R.B., K.P.W., and J.L.R.) began by reading the transcripts and making notes in the margins that signified instances of concepts from the focus group questions (*e.g.*, risks/benefits of research participation, preferences for website content) or that reflected a need or desire for specific program content. These concepts were used to create a coding framework that was applied to the transcripts. Coded data were imported into NVivo 10 software (QSR International, Pty. Ltd.) for data organization and queries. Memos were used to summarize findings. The current report describes the formative results of the focus group data pertaining directly to the desired content, format, and features of a web-based program; qualitative analyses of the data pertaining to attitudes and perceptions regarding the three types of studies and ethical concerns are ongoing and will be reported separately.

Phase 2 of the study involved designing a web-based education-to-action program based on our cumulative research findings and the specific guidance obtained in focus groups. The self-guided program consisted of four modules focusing on genetic/biobank research, CTs, medical CR studies, and research ethics. The decision to focus on these four modules was driven by the overall study aims and further supported by focus group findings indicating limited understanding of the research types (particularly CR and genetic/biobank research) as well as concern regarding the treatment

and protection of human subjects. Content for the four modules was compiled by three members of the study team (C.R.B., K.P.W., and J.L.R.). The content summarized descriptive information on the topic; for instance, definitions of biobank research or CTs, with emphasis on addressing common concerns or questions arising from focus group discussions (e.g., perceptions that individuals must have a particular disease to participate in a CT and concerns regarding who can access biobank data). Modules were compared against design and usability preferences given by focus group participants, including those related to program length and desire for multimedia components in the modules. The web-based program was created with assistance from a global technology development company. Before testing, a prototype of the program and various screenshots were presented to the Central Area Links leadership. A final round of pre-testing was conducted by several individuals at Mayo Clinic and The Ohio State University (OSU) to ensure the program's usability, and then the module content and assessments were launched on an external platform hosted by OSU.

The program was tested and evaluated in phase 3. Eight chapters within the Central Area were selected by the Central Area Director (A.S.) for program testing based on chapter size (including small, medium, and larger chapters with regard to membership numbers), membership demographics (members who are more active in the organization, representing younger and older members, *etc.*), and location (including both urban and rural chapters that were near a medical campus/cancer center). To encourage participation, chapters achieving participation rates of 80%, 90%, or 100% (based on the proportion of active members invited from each chapter) received a stipend to use toward community-based programming, with higher rates earning larger stipends. Membership lists were obtained for the eight selected chapters to determine participation rates, and invitations to complete the education-to-action program were sent electronically to chapter presidents, who informed their membership of the opportunity to participate. The program remained open for a 2-month period, after which the web link became inactive to enable the data to be downloaded for analysis.

Results

Phase 1: Formative findings on program content and design preferences

Participant characteristics. A total of 34 African American women participated in the focus groups, representing nine states and 19 different Links chapters in the Central Area. Women reported between 1 and 34 years of membership (mean = 12.6 ± 9.3 years; median = 11) with The Links. All participants were college educated (Bachelor's degree) or beyond, with 47% of the sample holding a doctoral or professional degree; all participants reported having health insurance coverage. Fifty-three percent ($n = 18$) of participants were retired, while 35% ($n = 12$) were employed full-time. Participants ranged in age from 42 to 82 years (mean = 62.4 ± 9.2 years; median = 63); 53% ($n = 18$) were married, 23% ($n = 8$) were divorced, 15% ($n = 5$) were single/never married, and 9% ($n = 3$) were widowed. Eighty-five percent ($n = 29$) reported no prior participation in health-related research.

Formative findings. Analysis of the focus group transcripts revealed that women wanted a future program to provide information on "the different types of studies, really defining what they are, how they are different, how they are the same, what is involved...are you just doing paper-work...are you going to have to provide specimens." Women expressed more concerns about how information is collected, used, and shared by investigators than with personal mistreatment in research regardless of the type of study (*i.e.*, GEN, CR, or CT) or the kind of information (social, health, or genetic) collected. There was support for including a research ethics component in the program, as these participants state: "I think that being up-front about the ethical piece also gives the site more credibility, you know, that we haven't forgotten about those things, but here is why there's reasons to kind of move beyond" and "I'd just come straight at it...not like fine print, like you have to dig for it, because then you're starting to get suspicious again."

With regard to program features, focus group participants emphasized brevity, security, being user friendly/easy to navigate, and inclusion of personal testimonies. "I don't want a lot of text. I don't want to read. I need an introduction, something that engages me, from someone who looks like me...then I'm inclined to...move forward." Further guidance included the importance of "coming from a positive point of view," providing information "that affirms the Black woman," and positive reinforcement in the program itself "saying you are doing a good job, you are halfway done...that would inspire me to keep going."

Phase 2: Program development

Each module included a pre- and post-test, assessing knowledge, familiarity, and attitudes and, for the three study types, willingness to participate in that particular type of study. The four modules contained factual information in an engaging format that included text, audio, and external web links for more information. Table 1 shows the topics in each module. A simple navigation pane on the program dashboard guided the participant through the program and included a visual display of progress toward program completion. The program began with a welcoming audio-recorded message from one of the principal investigators of the study (K.P.W.) and included professional photographs of several members of the study team. The introductory message conveyed that the program was developed for The Links with funding from the National Institutes of Health and invited participation in the program as part of an ongoing study. The program required secure log in and affirmation of consent to participate in research before enabling the participant to access program content and activities.

Phase 3: Education-to-action program testing

Participant characteristics. A total of 244 Central Area Links members completed the program (77% response rate overall); all participants were African American women. Over 98% were college educated (Bachelor's degree) or beyond, with 37% of the sample holding a doctoral or professional degree. Participants ranged in age from 28 to 76 years (mean = 55.3 ± 11.3 years); 75% ($n = 182$) were married, 11% ($n = 26$) were single/never married, 9% ($n = 21$) were divorced, and 4% ($n = 11$) were widowed, with the

TABLE 1. OUTLINE OF EDUCATION-TO-ACTION PROGRAM TOPICS BY MODULE

<i>Module</i>	<i>Topics</i>
Clinical trials	Purpose and types of clinical trials Understanding clinical trial phases How to get information about participating in a clinical trial Examples of clinical trial studies
Medical record/chart review research	Rationale for conducting chart review research Protecting patient privacy in chart review studies How to know if your medical records are being used in research Examples of chart review studies
Genetic/biobank research	Biospecimen types, acquisition, storage Biospecimen identification/linkage to medical records Considerations when thinking about participation in a biobank Understanding tiered consent for biospecimen research Genetic discovery
Research ethics	Human subjects' protections Institutional review boards Informed consent Research participant rights

TABLE 2. SELECTED OPEN-ENDED/WRITE-IN COMMENTS REGARDING THE CONTENT WITHIN THE FOUR PROGRAM MODULES

<i>Program module</i>	<i>Participant comments</i>
Clinical trials	<p>"I enjoyed the information regarding clinical trials. For some reason I didn't know that people who were not ill could participate. It makes sense to have someone who has the illness in the family yet does not have it to participate."</p> <p>"I have experience participating in a clinical trial, so I could relate more. Despite the information in this website, it still feels risky to participate in any study other than a chart review, because of the history of abuse that has happened to African Americans and Jews."</p>
Medical record research	<p>"This module seems most "layman"-friendly. I can easily relate it to my medical experience, i.e., anyone who's been to a doctor knows what a chart is."</p> <p>"It provides for an additional means of participation which might make it easier for folks to participate. Also, I was not aware of Chart Review studies."</p> <p>"I have been asked to participate in chart reviews. I was leary (<i>sic</i>) because of my concerns of the information being misused. Now that I have been informed that the data can be used without my consent in most states, I might as well participate. I was aware that names are not identified, but I still am little leary (<i>sic</i>), particularly when research is being conducted by majority institutions with few African Americans on staff. My opinion is based on personal experience."</p>
Genetic/biobank research	<p>"When I first started reading this section, I felt a little uneasy; however after reviewing the information, I was able to understand how this information could be of benefit to me and my health. As a participant in this survey, I am encouraged to see the opening up of opportunities for African American Women. Historically, we have not taken advantage of programs designed to detect, address or prevent problems related to our health. In many cases we are afraid of what might be discovered, therefore, there is a failure to take advantage of various services. This module appeared to have been easier for me to relate to. I was able to make the connection to why it is important to become an involved participant and how being a participant not only is instrumental in my health, but it provides a means for shaping women health particularly for African American women... Thank you for including me in this worthwhile endeavor."</p>
Research ethics	<p>"The module provided the confirmation I needed to completely re-trust a scientific research system that was once broken and unjust. The skepticism was instilled by stories of the past, in addition to, shared experiences by family members."</p> <p>"I enjoyed all of the modules. The research ethics was interesting, just not sure how strongly it is enforced based on the Lacks case, which was fairly recent in our history. Not sure some discrimination is not still occurring with research."</p>

remainder (1%, $n=4$) choosing not to report marital status. Nearly one-fourth (24%, $n=58$) of women reported not having children, while 35% ($n=85$) reported two children, 23% ($n=56$) reported one child, and 18% ($n=45$) reported three or more children. Ninety-eight percent ($n=239$) of the sample reported adequate health literacy.^{26,27} Sixty-nine percent reported no prior participation in health-related research.

Program acceptability. Participants spent a median of 33 minutes (Interquartile range: 16, 77.5) in the program and reported high levels of satisfaction with the program. Seventy-five percent rated content relevancy and usefulness as “excellent” or “very good”, and 72.9% gave “excellent” or “very good” ratings in terms of the website’s credibility. In terms of being easy to understand or read, 68.4% rated the website as “excellent” or “very good,” although some participants noted in their comments that the content may be too much for a general population. The vast majority (79.5%) said they would probably or definitely recommend the website to women they know. The program contained text boxes at the conclusion of each module to allow open-ended comments regarding module content to be typed in; commenting was encouraged to assist the investigators with refining the program content in future iterations. Selected comments, both laudatory and critical, regarding each of the four program modules are shown in Table 2.

Research perceptions and knowledge. The percent of women indicating that they “definitely” or “probably” intend to participate in research increased from 9.4% to 19.5% and 27.1% to 49.8%, respectively, after program completion ($p<0.001$). While few women rated their opinion of each of the three study types as “very positive” before beginning the program, upon completing the program, attitudes were more favorable toward CTs, medical record research, and genetic/biobank research (Table 3). Furthermore, willingness to participate, if asked, increased upon program completion for each of the study types (Table 4).

Before completing the program, many women reported having “little or no understanding” of the three types of studies (66% GEN, 62.9% CR, and 40.7% CTs), whereas after program completion, the proportion with “little or no understanding” decreased to 24.9%, 18.4%, and 15.5%, respectively, suggesting greater perceived understanding. Factual knowledge tests administered within the program lent support to these perceptions. A total of 21 items assessed knowledge of CTs (8 items), genetic/biobank research (8 items), and CR studies (5 items). Items included true, false, and “don’t know” response options, with “don’t know” responses scored as incorrect. Example items (with correct response) for CTs included: “People must be diagnosed with a particular disease to be eligible for a clinical trial (false),” “Information about clinical trials is only available through healthcare providers (false),” and “Early phase trials include a smaller number of people than later phase trials (true).” For GEN, example items included: “If something bad is found in a blood sample given for research, the participant will automatically be notified (false),” “African Americans are under represented in biobanks (true),” and “DNA can be extracted from a saliva sample (true).” Knowledge items for CR included: “You will always be asked before your medical record is used for research (false),” “Because names are

TABLE 3. PRE- AND POST-PROGRAM ATTITUDES TOWARD CLINICAL TRIALS, MEDICAL RECORD RESEARCH, AND GENETIC/BIOBANK RESEARCH

Type of research	Pretest (%)	Post-test (%)
Clinical trial		
Very negative	0.9	0.9
Somewhat negative	5.6	1.3
Neutral	26.8	16.4
Somewhat positive	36.8	37.6
Very positive	28.6	42.5
Choose not to answer	1.3	1.3
Medical record research		
Very negative	2.7	0.9
Somewhat negative	11.5	1.8
Neutral	41.2	21.1
Somewhat positive	22.6	30.9
Very positive	15.0	43.0
Choose not to answer	7.1	2.2
Genetic/biobank research		
Very negative	0.8	0.9
Somewhat negative	2.1	0.9
Neutral	52.5	19.2
Somewhat positive	24.4	34.1
Very positive	14.3	42.8
Choose not to answer	5.9	2.2

Post-test attitudes were more favorable than pretest attitudes for all three types of research using the Wilcoxon signed-rank test (all $p<0.01$).

removed from the data files used by researchers, this type of research does not require any type of approval or oversight (false),” and “Chart review studies are considered ‘minimal risk research’ (true).” Mean knowledge scores (% correct) improved from pre- to post-test for each of the study types (all $p<0.001$), with the largest mean difference (increase) in post-test knowledge scores for CR studies (Table 5, rows 1–3).

With regard to the research ethics module, results showed greater confidence from pretest to post-test in the ability to identify the rights of research subjects and more favorable attitudes toward current processes in place to protect human research participants from harm (both $p<0.001$). Agreement (combining the responses “agree” and “strongly agree”) with the statement “research conducted in the U.S. is ethical” increased from 54% to 75.9% ($p<0.001$). Knowledge scores across eight items addressing informed consent and research oversight also significantly improved upon program completion (Table 5, last row).

Postintervention action and dissemination. The program included information about clinicaltrials.gov and Research Match, a disease-neutral recruitment registry designed to match potential participants/volunteers with researchers.²⁸ Six months after the education-to-action program closed, 15 women reported on their activities since completing the program. Twelve women reported talking to others (friends, family, other members of The Links, and colleagues) about health-related research, three actively sought opportunities to participate in research, four visited the clinicaltrials.gov website, and one woman registered with ResearchMatch.

TABLE 4. PRE- AND POST-PROGRAM WILLINGNESS SCORES FOR CLINICAL TRIALS, MEDICAL RECORD RESEARCH, AND GENETIC/BIOBANK RESEARCH

<i>Type of research</i>	<i>Pretest n (%)</i>	<i>Post-test n (%)</i>	<i>Mean difference (SD)</i>	<i>p</i>
Clinical trial			0.22 (0.56)	<0.001
Not at all willing	10 (45.0)	4 (1.8)		
Not very willing	35 (15.6)	26 (12.0)		
Somewhat willing	148 (66.1)	126 (58.1)		
Extremely willing	31 (13.8)	61 (28.1)		
Medical record research			0.52 (0.76)	<0.001
Not at all willing	19 (8.8)	6 (2.8)		
Not very willing	50 (23.0)	19 (8.7)		
Somewhat willing	112 (51.6)	100 (45.9)		
Extremely willing	36 (16.6)	93 (42.7)		
Genetic/biobank research			0.33 (0.62)	<0.001
Not at all willing	18 (7.9)	9 (4.1)		
Not very willing	31 (13.5)	11 (5.0)		
Somewhat willing	146 (63.8)	127 (58.0)		
Extremely willing	34 (14.8)	72 (32.9)		

SD, standard deviation.

Of the eight invited chapters, all achieved a participation rate that earned a stipend, which essentially extended the action goal of the education-to-action program and involved dissemination of program content to constituents whom The Links serve through their volunteer commitments. These chapters were given the opportunity to showcase their community-based dissemination projects at the 2017 Central Area Conference. The projects ranged in scope from partnering with an academic health system to cohosting a day-long health disparities conference that included churches and other African American female organizations to an intimate lunch-and-learn for parents whose children participated in

The Links-sponsored education enrichment program at a local elementary school. It is estimated that over 900 African American individuals were reached outside of The Links organization.

Discussion

A novel, online education-to-action program targeting professional African American women was successful in improving knowledge, attitudes, and intent to participate in biomedical research. Although short-term measures of individual participant's actions following program completion

TABLE 5. PRE- AND POST-PROGRAM KNOWLEDGE SCORES FOR CLINICAL TRIALS, MEDICAL RECORD RESEARCH, GENETIC/BIOBANK RESEARCH, AND RESEARCH ETHICS

<i>Type of research</i>	<i>Pretest score (% correct of nonmissing responses)</i>	<i>Post-test score (% correct of nonmissing responses)</i>	<i>Mean difference (SD)</i>	<i>p</i>
Clinical trial			12.72 (20.31)	<0.001
N	231	226		
Mean (SD)	60.2 (19.4)	72.8 (19.8)		
Median	62.5	75.0		
Q1, Q3	50.0, 75.0	62.5, 87.5		
Medical record research			15.96 (23.86)	<0.001
N	226	223		
Mean (SD)	66.1 (25.1)	82.1 (23.7)		
Median	80.0	80.0		
Q1, Q3	60.0, 80.0	80.0, 100		
Genetic/biobank research			5.62 (16.78)	<0.001
N	238	229		
Mean (SD)	75.6 (18.3)	81.3 (19.9)		
Median	75.0	87.5		
Q1, Q3	62.5, 87.5	75.0, 100		
Research ethics			8.90 (20.69)	<0.001
N	227	222		
Mean (SD)	78.6 (23.8)	87.5 (18.8)		
Median	87.5	93.8		
Q1, Q3	62.5, 100	87.5, 100		

showed only modest activity with regard to actual enrollment in a study or registry, participants reported engaging others in conversations about research. At the level of the organization, Central Area chapters of The Links that were awarded stipends for high program participation were highly engaged in disseminating program information to their constituents through workshops and word of mouth. These findings are consistent with the oral tradition among African Americans noted by some participants in the focus groups and emphasize the importance of positioning such efforts within the context of a community-based organization to increase program impact and reach. Additionally, these findings highlight the challenges of motivating short-term actual behavioral commitment (*e.g.*, registering in a volunteer database and enrolling in a CT) with a single educational effort. Extensions of the current work may benefit from longitudinal measures of specific behavioral outcomes to evaluate additional potential impact of the program.

There is a scientific imperative to increase minority representation in biorepositories available for genomic research,^{29–31} although classification of research participants using racial and ethnic categories designated by U.S. federal offices may be suboptimal, misleading, or even harmful for characterizing diversity in genetic and genomic research.^{32,33} Studies of receptivity to genetic research initiatives among African Americans have highlighted the importance of early and consistent engagement with the community as well as addressing concerns regarding ethical conduct and equitable distribution of benefits resulting from the research.³⁴ Our own work²⁴ and the work of others^{16,35,36} has shown that African Americans are receptive to participating in genetic studies if invited, but may require more time and effort to recruit. Programs such as the one developed in this study can potentially benefit recruitment efforts by mitigating doubt and filling key gaps in knowledge and understanding among those in the African American community who are reached by professional women in The Links.

Favorable shifts in attitudes, particularly toward studies involving biobanking and genetic analysis of biological samples, are an important and timely result of this work. Similar to Powell–Young³⁷ who surveyed members of the National Black Nurses Association, we identified concerns among members of The Links that genetic research can be used to discriminate against minorities. However, participants in both of these investigations also recognized that minority participation in genetic research is important and that national organizations are in a unique position to foster awareness.³⁷ Our study furthered this work by developing and testing an online program designed to provide education, information, and empowerment of African American women with regard to biomedical research.

Participants in this study were older, educated African American women belonging to a volunteer service organization. This may limit the generalizability of the findings; however, others have reported few differences in perceptions regarding medical research participation by age, gender, or level of education among African Americans.³⁸ Furthermore, this study was designed to develop and pilot test a program that educated and empowered professional African American women to engage in health-related research. Program development was responsive to needs identified in our prior work with The Links as well as many aspects pertaining to

content and design that were captured in focus groups. Achieving a 77% response rate among those invited to complete the program suggests receptivity and acceptability of the web-based program; however, improvements were also indicated. The pre–post study design limited the study's rigor; however, it afforded efficiency and simplicity and provided promising data as a foundation for further testing of the program in the context of a more rigorous study design.

Conclusions

This intervention implemented the train-the-trainer model, providing direct education to a select group of African American women (The Links) who have a continuous sphere of influence through the service they render in both their local and the broader African American community.

In conclusion, a brief, self-directed online program targeted toward professional, service-oriented African American women improved knowledge, perceptions of ethics, and intent to participate in biomedical research, including genetic studies involving biospecimen collection and use of health information from medical records. By leveraging academic/community partnerships such as in this research, communities of color can receive accurate information about biomedical research through education and dissemination efforts.

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