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# Recruitment practices for U.S. minority and underserved populations in NRG oncology: Results of an online survey $\stackrel{*}{\sim}$



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# ABSTRACT

*Introduction:* Cancer clinical trials (CCT) provide much of the evidence for clinical guidelines and standards of care. But low levels of CCT participation are well documented, especially for minorities.

*Methods and materials:* We conducted an online survey of 556 recruitment practices across the NRG Oncology network. Survey aims were 1) to learn how sites recruit minority/underserved populations; 2) to better understand the catchment areas of the NRG institutions; and 3) to aid in planning education programs for accrual of minority/underserved populations.

*Results:* The survey response rate was 34.9%. The most effective methods reported for recruiting minority/ underserved participants were patient navigators (44.4%) and translators (38.9%). All institutions reported using a mechanism for eligibility screening and 71% of institutions reported using a screening/enrollment tracking system. CCT training was required at 78.1% and cultural competency training was required at 47.5% of responding institutions. Only 19.9% of sites used community partners to assist with minority recruitment and just 37.1% of respondents reported a defined catchment area. Sites reported very little race and ethnicity data. *Conclusion:* This NRG Oncology online survey provides useful data for improvements in trial enrollment and training to recruit minority/underserved populations to CCT. Areas for further investigation include web-based methods for recruitment and tracking, cultural competency training, definition of catchment areas, use of patient navigators, and community partnerships. The survey results will guide recruitment training programs.

#### 1. Introduction

Clinical trial results inform clinical guidelines and standards of care that lead to improvements in patient care. However, minorities and the underserved, especially the elderly, are under-represented in clinical trials [1]. The situation is worsened when the disease under study disproportionately affects an under-represented population [2–7]. A recent multivariable analysis of 1797 women in four neoadjuvant systemic therapy trials by Warner et al. found that pathological complete

response rates did not differ by race or ethnicity when the treatment dose was correct [8]. However, this may not be true for all underserved populations or for all diseases. Because treatments may have differential effects across different populations, we cannot always assume that all trial results are generalizable to under-represented populations [9–12].

Barriers to minority participation in clinical trials occur at the eligibility, patient, provider, and system levels [13,14]. More stringent eligibility criteria in recent years have resulted in decreased accrual,

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lengthier study enrollment periods, and lower generalizability of trial results [15–18]. Physician level barriers include, but are not limited to, preference for a specific treatment, lack of time to enroll patients in clinical trials, and biases that certain patients will not be interested or compliant [19–23]. Distrust of the medical system, uneasiness with randomization, and concern regarding extra costs of participating in a clinical trial are examples of patient level barriers [24,25]. System level barriers include accessibility to a clinic with clinical trials and availability of applicable clinical trials [26,27].

We conducted an online survey to obtain data about training and recruitment practices for population groups represented across the NRG Oncology network to identify provider and system level barriers to cancer clinical trial accrual and current best practices in recruitment. Our aims were 1) to learn more about how sites recruit patients, especially minority/underserved populations; 2) to better understand the catchment areas of the NRG institutions in order to identify sites that care for minority/underserved populations; and 3) to identify areas in NRG where education/additional training for accrual of minority/ underserved populations is needed.

# 2. Methods

We developed an online survey instrument using several questions from previous surveys and from a literature review (Appendix A). The survey contained questions covering the following topics: methods/ practices used to improve cancer clinical trial recruitment, recruitment strategies that have worked for minority/underserved participants, recruitment strategies that have been tried but did not work well, methods for screening and tracking patient entries, and recruitment training. The instrument also covered questions about population demographics, specifically the racial and ethnic breakdown of the cancer patient population served by the institution and the racial and ethnic breakdown of the catchment area. The instrument was beta-tested on physicians, advocates, clinical research associates, data managers and statisticians prior to administering the survey to the NRG sites. It was then edited based on their responses. The survey took 15 min to complete.

In January 2016, an email containing a link to the online survey (Appendix B) was sent to each NRG Network Lead Research Associate and the Local Site Research Associates (556 research associates). Network Lead Research Associates were asked to verify whether or not all of their affiliate sites received the survey; if not, they were asked to forward the email and link to them. Only one person from each site (Institution CTEP ID) was allowed to complete the survey. It was recommended that the ideal respondent was the person most familiar with site recruitment practices, but respondents were allowed to collect information from colleagues as needed. Almost 2 weeks after distribution, the survey was promoted at the NRG Oncology semiannual meeting during the Clinical Trials Nurse/Clinical Research Associate Educational Session and several other sessions. A final reminder was sent on February 1, 2017, just prior to the closing of the survey on February 8, 2017.

As an incentive, respondents were given the opportunity to participate in a raffle. The raffle prize was \$1000 in travel funds dedicated to attend a future NRG meeting. To participate, research staff had to provide their name and email address, but this identifying information was not linked to the survey responses.

The online survey development software (SurveyMonkey, San Mateo, CA) did not allow respondents to save a partially completed survey. Therefore, the research associates were given explicit instructions to complete the survey in one sitting. In addition, a PDF document of the survey questions was included in the email distribution to facilitate data collection prior to initiation of the online survey responses if needed. After the survey closed, raw data of the survey results were downloaded from SurveyMonkey, and response distributions were tabulated using Microsoft Excel 2013. The respondents were not required

to provide an answer to each question to complete the survey, and so some data were missing for each survey item. Therefore, the percentages cited are reflective of the number of respondents for each individual question. Additionally, some questions allowed the respondent to choose more than one answer so they may be represented in several response categories per question.

# 3. Results

There was a 34.9% overall response rate, with 194 of 556 institutions from 41 states in the United States participating. More than 90% of the respondents were non-Hispanic white women, primarily in the roles of research nurse, clinical research associate, and program coordinator.

Responses indicated that varied methods were used to improve overall recruitment for cancer clinical trials (data not shown). Almost all respondents (89.9%) reported using communication/education methods to disseminate information about trials and cancer clinical trials recruitment. The top four communication/education methods were posting information on institutional websites, using patient navigators, distributing written materials, and using language translation services. A small proportion (12.2%) used incentives to improve recruitment including money, gift cards, and parking and travel reimbursements. Funding for the incentives came primarily from the sponsor; the second highest source of funding was the institution.

Methods and practices for recruiting minority/underserved trial participants are presented in Table 1. The most effective methods reported included the use of patient navigators (44.4%) and translators (38.9%) to assist with clinical trial education. Communication about clinical trial opportunities through postings on institutional websites (36.8%) and through written materials translated into languages other than English (36.1%) were also reported to be effective. Using incentives was reported more frequently to recruit minority/underserved participants than for overall recruitment, with 20.8% reporting the use of travel reimbursements, 16.7% reporting monetary incentives, and 10.4% covering parking fees.

Only 13.4% of respondents reported prior recruitment strategies that have failed (data not shown). Of those, the most commonly reported strategies that did not work were newspaper advertisements and flyers, although multiple failed strategies were listed. However, there was considerable overlap between successful strategies at one institution and failed strategies at another, including newspaper advertisements, institutional website, flyers, and incentives.

All 194 participating institutions reported a mechanism for eligibility screening. The individuals most commonly responsible for screening patients for eligibility included the research nurse (82%),

# Table 1

What Methods/Practices Work Best to Recruit Minority/Underserved Participants? (N = 144).

Answer Options	Response Percentage	Response Count
Patient navigators to assist with clinical trial education	44.4%	64
Translators available to assist with clinical trial education	38.9%	56
Communication on clinical trial opportunities on institution website	36.8%	53
Written communication on clinical trial opportunities translated into languages other than English	36.1%	52
Incentives for travel reimbursement	20.8%	30
Incentives-Monetary (unrestricted)	16.7%	24
Invitation letters sent to potential participants	13.9%	20
Incentives-Parking fee	10.4%	15
Video on clinical trial opportunities	6.3%	9

#### Table 2

Does your institution require cultural competency training for research staff? (N = 183).

Answer Options	Response Percentage	Response Count
Yes	47.5%	87
No	52.5%	96
If yes, how often?		
Once		7
Annually		43
Every 2 years		1
Every 3 years		3
Unsure/not answere	d	33

principal investigator (58.8%), and/or clinical research associate (50%). Most respondents also reported using a screening/enrollment tracking system (71%). The top five categories of data entered into the tracking system in order were the number of eligible participants that agreed to participate, the number that refused to participate, the total number that were eligible, the number of eligible participants that were offered a clinical trial, and the reason for refusal.

Mandatory cultural competency training for research staff was reported by 47.5% of the 194 responding institutions, with half of those sites reporting annual training (Table 2).In addition to cultural competency training, many responding institutions required training in clinical trial recruitment (Table 3). Of the respondents, 55.6% reported one-on-one cancer clinical trials recruitment training at their institution, 32.1% used outside courses either online or in the classroom, and 12.8% participated in online classes developed by the institution. No formal/required cancer clinical trials recruitment training was reported among 21.9% of the respondents.

Most (80.1%) of the 186 sites that answered the question regarding the use of community partners to assist with recruitment of minorities or the underserved answered in the negative. The community partners that were used included churches, community hospitals, and organizations such as the American Cancer Society.

There were 151 responses to the question "Do you have a defined catchment area for your institution/practice," with 85 (56.3%) choosing yes. However, only 56 (37.1%) of the 151 were able to explicitly define their catchment area. Geographic variances of the catchment areas ranged from a single county to five states. The responding sites reported very little race and ethnicity data. However, 57% of respondents reported a large population of other (not racial/ ethnic groups) under-represented populations in their catchment area. The top two categories reported were rural and elderly.

# 4. Discussion

The NRG Oncology online survey results provide insight into the minority/underserved recruitment and training practices at its member institutions. Our findings related to recruitment are consistent with the

#### Table 3

What training does your site offer in regard to cancer clinical trial recruitment for research staff? (N = 187).

Answer Options	Response Percentage	Response Count
One-on-one training at your institution	55.6%	104
Outside courses (classroom, online, other)	32.1%	60
Online classes developed by institution	12.8%	24
Classes on recruitment strategies	5.3%	10
Classes/information on health literacy considerations	4.2%	8
Other	7.0%	13
None	21.9%	41

existing literature. Most of the participating sites reported multiple recruitment modalities, reflecting the results of other studies that have recommended interventions to address barriers at multiple levels [14,28,29]. Furthermore, it is encouraging that most sites used communication and education methods to improve overall recruitment. Basche et al. and Kimmick et al. reported that increased communication about trials to community oncologists and prospective enrollees could improve elderly participation in clinical trials [3,30]. The most commonly reported successful strategy for minority recruitment among our respondents was patient navigation. This finding agrees with Fouad et al. and Cartmell et al. who also reported success in minority recruitment to clinical trials using patient navigation [31,32]. Our survey results also showed that most reporting sites track their screening/enrollment data. Ko et al. demonstrated that a formal process of tracking cancer clinical trials screens using an electronic medical record can identify strategies for increasing cancer clinical trials enrollment among a vulnerable patient population [33].

In regard to staff training, almost half of our respondents reported a requirement for cultural competency training for research staff and clinicians. The importance of this training has been shown previously. Joseph and Dohan [29] used ethnographic methods to identify how institutional barriers deterred trial enrollment in a public hospital outpatient breast cancer clinic [29]. Otado et al., Harrigan et al. and Ezeugwu et al. reported that culturally competent approaches to recruitment were essential to improve recruitment of under-represented groups to clinical trials [34–36]. Thus, although it was reassuring to see that almost half of the institutions provided this type of training, we also now know that there is room for improvement that could substantially affect minority recruitment. Our survey also revealed that, surprisingly, 21.9% of sites offer no training at all in clinical trial recruitment for research staff.

It was disappointing that only 28.9% of the 194 participating institutions provided a defined catchment area. Respondents may have been unaware of their catchment areas and were not able or were unwilling to retrieve it from institutional sources. Without knowing the population being served, it is hard to assist, perform outreach to, and enroll participants from that population in clinical trials.

Unfortunately, few sites reported working with community partners to assist with minority recruitment. However, this is not unexpected and is in line with findings in the current literature. Tanner et al. surveyed principal investigators working in five main academic centers in South Carolina and found that clinical trial teams rarely promote clinical trial research outside of the medical setting or reach out to community organizations [37]. However, integrating research in the community is an important strategy to recruit diverse populations [38]. Heller et al. and Napoles et al. reported that multiple and flexible strategies targeting providers and participants at institutions as well as within communities might be needed to enroll under-represented populations into trials [39,40].

The NRG Oncology online survey had many strengths. It benefitted from a very large member base, which provided access to a large number of sites, yielding 194 responses. The power of the NCTN structure will be utilized by involving the other adult-serving NCTNs (SWOG, Alliance for Clinical Trials in Oncology, and ECOG-ACRIN Cancer Research Group) to participate in solving the problem areas identified by the survey.

However, the survey was not without limitation. Most concerning was the survey response rate of 34.9%. One factor that may have contributed to the low response was the requirement for survey completion in one session. This was necessitated by the online survey development software. Although a PDF of the survey questions with explicit instructions was distributed to allow data collection prior to initiation of the survey, this limitation may nonetheless have contributed to the low response rate. One consequence of a low response rate is that these survey results may not reflect the overall NRG membership. The paucity of race and ethnicity data provided by the responding sites made it impossible to draw any meaningful conclusions about the racial and ethnic make-up of the populations that should be served. Another limitation is that the survey was not psychometrically evaluated for validity and reliability, although it was pilot tested and reviewed by research personal. Furthermore, the strategies listed as "successful" had no qualifying metrics to determine their true success (e.g., number of generated enrollees), and very few sites listed strategies that did not work. Although it is possible that sites used only tried and true methods, it is also possible that the failed strategies and those with a poor response were not recognized or remembered.

Information from this NRG online survey will be used to improve trial enrollment and shape future training efforts to enhance the cancer clinical trials recruitment of minority and other underserved populations. Specific areas that merit further investigation include web-based methods for cancer clinical trials recruitment and tracking, as well as the specific needs of other (not racial/ethnic groups) under-represented populations. Correspondingly, the American Society of Clinical Oncology released a position statement on July 1, 2017, on strategies for reducing cancer health disparities among sexual and gender minority populations [41]. Training of investigators and staff is a continuing need that can be fulfilled at both the semi-annual meetings of the NCTNs and on their websites. Topics for this training include cultural competency, definition of catchment areas, use of patient navigators in recruitment activities, and partnering with community members for enhanced cancer clinical trials enrollment. Increasing diversity in membership and leadership in oncology research organizations may also enhance diverse cancer clinical trials participation.

In response to these survey results, the NRG Health Disparities Committee (HDC) is collaborating with the SWOG Recruitment and Retention Committee to provide a tool to assist sites in defining the catchment areas for their practices and institutions. This tool will provide methods to calculate the catchment area for community practices and to locate the defined catchment area for a large or academic institution. The NRG HDC also recently sponsored a presentation on "The Role of Physician Communication in Accruing Diverse Patients to Cancer Clinical Trials" at the semi-annual NRG Oncology meeting in July 2017. A number of other recruitment and training programs are being designed based on these survey results.

In conclusion, this survey of NRG institutions sheds light on the individual recruitment practices for cancer clinical trials of the member institutions. These responses also identified areas where additional training and recruitment support are needed. The survey results provide useful data that will shape future training efforts to recruit minority and other underserved populations to cancer clinical trials.

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### Appendix A. Supplementary data

Supplementary data related to this article can be found at http://dx. doi.org/10.1016/j.conctc.2018.03.003.

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