



Anthony Droege. *Dragon's Bowl*. Oil on board, 29½" × 39¼".
Courtesy of Longstreth-Goldberg ART, Naples, Florida.

*A specific, culturally relevant,
comprehensive clinical trials
education curriculum
can improve knowledge
about such trials in
underserved communities.*

Lessons Learned While Developing “Clinical Trials Education for Native Americans” Curriculum

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This paper highlights lessons learned while developing the Clinical Trials Education for Native Americans (CTENA) curriculum. The CTENA is a culturally specific clinical trials education curriculum that evolved from another ongoing NCI-supported project, Clinical Trials Education for Colorado Providers. The multicultural team learned many lessons while developing, pretesting, and revising this curriculum. These include allocating sufficient time and resources to tailor presentations for diverse tribal settings and workshop participants, addressing barriers to participation in clinical trials through culturally appropriate strategies, providing information to foster informed decision making related to participation, and writing as a team to increase cultural breadth of examples and interactive experiences.

There are multiple challenges to developing and implementing a culturally acceptable curriculum on clinical trials within medically underserved communities. Both the multicultural team and the curriculum benefited from the collaborative process, resulting in a culturally relevant clinical trials curriculum that will assist Native Americans to make informed choices about clinical trials participation. The lessons shared here, which may need to be modified to be culturally relevant to other underrepresented communities, may be beneficial to others developing similar curricula for other medically underserved populations.

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Introduction

The purpose of this paper is to describe lessons we have learned while developing a clinical trials education curriculum for Native Americans. Through a process of collaborating together in a comfortable environment away from the intrusions of everyday work life, the multicultural grant faculty was able to develop a comprehensive, culturally relevant, and sensitive clinical trials education curriculum that meets the needs and interests of a wide variety of Native American healthcare providers, advocates, tribal leaders, and current and former patients and their families. The lessons described below delineate strategies to move beyond the norm of being mired and preoccupied with identifying barriers to clinical trials recruitment and retention. Instead, the goal is to find solutions to facilitate clinical trials knowledge and to reinforce the importance of making an informed choice about participation in clinical trials. We believe that these lessons will be of value to others involved in developing and implementing similar curricula for use with medically nonrepresented or underrepresented populations.

Background

The Continuing Increase in Cancer Among Native Americans

Although cancer incidence is decreasing in the general population, it continues to increase among American Indians and Alaska Natives.¹ Incidence rates among Alaska Natives have exceeded "US All Races" rates for most cancer sites and are similarly increasing for Canadian bands.^{2,3} Since World War II, nearly every American Indian and Alaska Native community has experienced suffering and death from this disease.^{3,5} In the last half of the 20th century, cancer has become the leading cause of death for Alaska Native women and is the second-leading cause of death among Alaska Native men.^{6,8} Cancer is currently the third-leading cause of death for American Indians and Alaska Natives of all ages⁹ and is the second-leading cause of death among American Indians (both sexes) over 45 years of age. Cancer rates that were previously reported to be lower in American Indian and Alaska Natives have been shown to be increasing in the past 20 years.¹⁰ The relative 5-year survival data for American Indians are among the poorest for all cancer sites combined of any racial group in the United States, such as African Americans, whites, or Hispanics. When compared to non-Indian peoples in the Southwest, even cancers in American Indians diagnosed with early stages result in poorer survival.¹¹

Underutilization of Clinical Trials

It is the general belief of the cancer care community that treatment provided through a clinical trial represents the best possible care that a cancer patient can receive. Unfortunately, less than 5% of all eligible cancer patients participate in clinical trials, and when looking at minority participation, the numbers are even lower.^{12,13} Patients on clinical trials receive closer follow-up and more prompt interventions of side effects, leading to decreased morbidity and mortality, increased survival, and an overall increase in quality of life (personal communication, Harold Freeman, MD, Chairman, President's Cancer Panel).

Medically underserved populations are often excluded from clinical trials because of the belief held by some healthcare providers that the medically underserved are less likely to comply with study protocols and treatment guidelines. Additionally, many barriers exist that make medically underserved populations less likely to consider enrollment. One of the most important is lack of information about clinical trials participation and access. Indeed, the National Native American Cancer Survivors' Support Network, a program developed to improve survival from cancer and to enhance quality of life after cancer diagnosis for patients and their loved ones, found that almost none ($n = <5$, ~2%) of the 240 breast cancer patients enrolled in the Network recalled being provided information about cancer care clinical trials. This is in direct contrast to the findings of the 2000 Harris Interactive Poll on Clinical Trials in which approximately 25% of the cancer patients ($n = 6,000$) who were interviewed for the poll recalled being provided with at least some information about clinical trials participation.¹⁴

Based on preliminary data from the National Native American Cancer Survivors' Support Network, American Indian and Alaska Native patients are finding access to quality care difficult at best. From the Survivor Network's perspective, clinical trials information is viewed as a way to help patients access the existing standard of care, which many currently are not receiving. It is important for Native patients as well as other medically underserved and poor patients to be provided with clear, understandable information about treatment trials as well as other types of clinical trials in order to facilitate access to quality cancer care.¹⁵ In addition, although the barriers to participation have been well enumerated, culturally acceptable recruitment strategies to address these barriers remain insufficient.

The 2000 Harris Interactive Clinical Trials Poll

In 2000, the sponsors of the Summit Series on Clinical

Trials commissioned a survey of individuals with cancer to assess their participation in and beliefs about cancer clinical trials. Approximately 6,000 cancer patients were surveyed, including an oversample of African Americans and Hispanics. Study results showed that of those who responded to the poll, slightly less than 25% knew or recalled that they had ever been informed of clinical trials. Of those who did not believe they had been approached, 75% said they would have considered participation had they known it was possible. Fewer minorities recalled discussing clinical trials with a provider, but there were essentially no racial or ethnic differences in terms of willingness to consider participation.¹⁴

In addition, as a component of the Clinical Trials Survey, 1,000 adults in a national probability sample were also assessed for their attitudes about clinical trials participation. In this survey, which was weighted to reflect the adult population of the United States, 32% indicated they would be very willing to participate in a clinical trial, and an additional 38% indicated an inclination to participate. Findings from this component of the survey identified a lack of presentation or discussion of clinical trials as a major deterrent to overall participation.¹⁶

Clinical Trials Education for Colorado Providers

In 1999, the University of Colorado Comprehensive Cancer Center was awarded a 4-year grant (“Clinical Trials Education for Colorado Providers,” R25 CA82714, NCI, PI Linda U. Krebs) to increase healthcare provider referrals of women and minorities to cancer care trials. The primary mechanism to achieve this goal is the development, implementation, and evaluation of clinical trials educational interventions for healthcare providers that incorporate both culturally and geographically congruent materials for the greater Colorado region and also promote cultural competence in healthcare providers. The curriculum is referred to as the “7Cs” — the Colorado Culturally Competent Clinical Cancer Care Curriculum. It includes 18 objectives divided into 3 classifications: universal, basic, and intermediate. This ongoing study provided the basis from which the curriculum of the Clinical Trials Education for Native Americans (CTENA) evolved. Additional information about this curriculum, including delineation of the 18 objectives, can be found at <http://www.clinicaltrialseducation.org>.

Clinical Trials Education for Native Americans

In 2000, we (L.U.K., L.B.) were awarded a 1-year grant from the Cancer League of Colorado to develop a clinical

trials education curriculum for Native Americans. Since this cultural adaptation was relevant to the ongoing “The American Indian/Alaska Native Initiative on Cancer” (“Spirit of E.A.G.L.E.S., U01 CA86098), the Mayo Clinic subcontract to Native American Cancer Research was modified to help support CTENA curricular development, pretesting, and revision. This educational curriculum is designed for both the lay population and the providers who work with Native communities. The CTENA provides easy-to-understand, interactive educational workshops to increase Native Americans’ awareness and understanding of clinical trials and to facilitate decision making about clinical trials participation. It is derived from, and serves as a companion to, the “7Cs” curriculum that is designed solely for healthcare providers.

Six intertribal focus/working groups met to determine what is currently understood about clinical trials research. Each focus/working group included an average of 6 Native participants who were healthcare providers, Community Health representatives, tribal leaders, cancer patients, or caregivers to Native cancer patients. The members of these groups also identified priority issues to be addressed through the subsequent curriculum. Based on findings from these 6 group meetings, 12 objectives were identified to be included within the curriculum (Table 1). By July 2001, all 12 objectives had been pretested, revised, and reformatted for PowerPoint presentations. The Figure depicts the process used to develop, pretest, and revise the 12 objectives.

The CTENA curriculum is designed to be implemented in conjunction with ongoing professional or

Table 1. — Workshop Objectives for “Clinical Trials Education for Native Americans” Curriculum

NA-1	Examine common reasons for and against Native American communities’ participation in research studies.
NA-2	Describe the importance of including Native Americans in cancer care trials.
NA-3	State the purpose and importance of clinical trials.
NA-4	Describe the types and purposes of cancer clinical trials.
NA-5	Explain the phases of cancer clinical trials.
NA-6	Examine common Native American myths and beliefs related to cancer clinical trials.
NA-7	Identify local and national resources for accurate information about cancer and clinical trials.
NA-8	Examine the potential benefits and drawbacks of participation in cancer treatment clinical trials.
NA-9	Describe the impact of Native cultural perspectives on health and the experience of cancer and clinical trials.
NA-10	Examine selected ethical, social, cultural, spiritual, and legal issues related to Native American’s participation in clinical trials.
NA-11	Describe benefits and drawbacks in using traditional Indian medicine in cancer care.
NA-12	Identify the Tribal Research Approval Process relevant to clinical trials.

community meetings (pre, post, or as included sessions) or may be presented as a “stand-alone” educational program. Objectives identified to be of greatest relevance to the attending audience are selected from the list by program organizers. The selected objectives are then combined into an educational module or lesson for presentation. Ideally, a 3-hour period is made available for each clinical trials workshop. Since completion, components of the curriculum have been presented in a variety of settings and to diverse groups of Native Americans and others, including members of the Association of American Indian Physicians (AAIP). Post-workshop evaluation results from the 2002 AAIP meeting noted a significant ($P=.02$) increase in clinical trials knowledge as

well as numerous qualitative remarks relating to the overall value and usefulness of the information presented in the 3-hour session. Additional information about this project and the PowerPoint presentations for each of the objectives can be found at either <http://members.aol.com/natamcan> or <http://www.clinicaltrialseducation.org>.

Lessons Learned

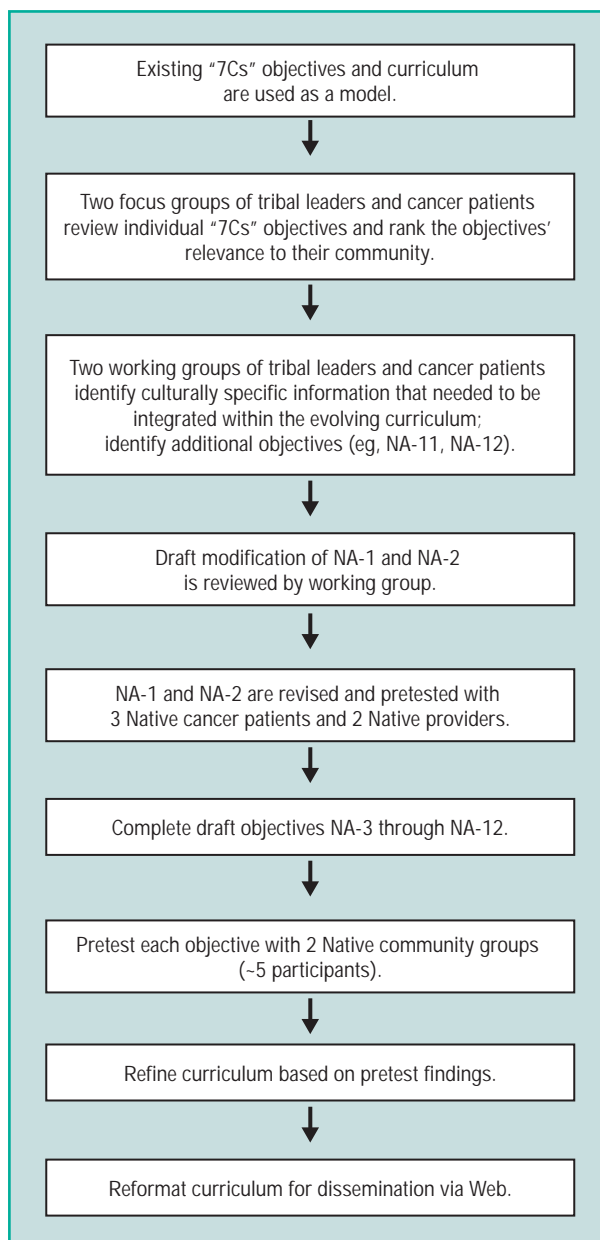
As the preceding information has demonstrated, the reasons for the lower participation of medically underserved populations in clinical trials is complex. A specific, culturally relevant, comprehensive clinical trials education curriculum has the potential to address some of these complexities and promote increased knowledge about clinical trials in underserved communities. The grant faculty set out to create such a curriculum for Native Americans, with the goal of promoting informed decision making about clinical trials participation. While developing this curriculum, several lessons have emerged that we believe helped us to create a useful and relevant clinical trials education curriculum. We also believe that these lessons have the potential to benefit other investigators and faculty in the development of similar curricula for other underserved populations.

Lesson #1: Support Efforts to Overcome Barriers to Participation in Clinical Trials

The current literature cites numerous barriers for the recruitment and retention of women, minorities, and the medically underserved to cancer care trials.¹⁷⁻³¹ Professionals often oversimplify this process and sometimes act as if identifying a precise barrier will result in a “quick fix” to the problem. This is not going to happen. Listing barriers is relatively easy, particularly when compared to identifying solutions. Rather than continuing to identify and list barriers, more effort needs to be directed to finding culturally acceptable ways to address those barriers. The challenge remains to establish successful, practical, and culturally respectful strategies. For each barrier, training for clinicians and community workers alike must raise questions such as, “What can we do about this barrier? How can we address it?”

Lesson #2: Shift the Emphasis on Measuring the Outcomes of Clinical Trials Education Efforts

The expected “bottom line” of clinical trials education is to increase the number of medically under-



Development process for the culturally specific clinical trials curriculum.

served individuals recruited and retained in a clinical trial. While increased participation is an essential long-term goal, the primary goal should be to educate about clinical trials so that patients have the opportunity to make a fully informed decision about participation. For programs that are developing curricula, the measure of success should not be based solely on enrollment, but based on the number of people reached and informed decisions made. Thus, additional measures need to be in place to document the full range of experience of individuals and providers, including awareness of clinical trials, decision-making determinants, and adherence with recommendations.

Lesson #3: Invest the Time, Resources, and Creativity Needed to Tailor Presentations and Materials for the Intended Audience

We had anticipated being able to base the “7Cs” and CTENA curricula on the NCI Cancer Clinical Trials Education Program (CCTEP).³² However, the information we sought in the original CCTEP was often difficult to find, unavailable, or inconsistent. For those developing new curricula, we strongly recommend taking the time to review and incorporate, as possible, the NCI Clinical Trials Education Series (CTES) materials developed by the NCI to replace the original CCTEP. The NCI CTES was released December 2001 and is a significantly more helpful resource. It is reformatted, better organized, and easier to use. The CTES replaces the CCTEP and consists of a variety of components that can be ordered individually at <http://www.cancer.gov> or by calling 1-800-4-CANCER. One of the components is a CD-ROM with 3 slide presentations: the first is for members of the public or health professionals who are not yet familiar with cancer clinical trials, the second is a community presentation that is listed on the NCI Web site as “low literacy,” and the third is a program for health professionals already familiar with clinical research principles.

Although all of these presentations are useful, the “7Cs” team was concerned that the high reading level and complex material and format of the “low-literacy” community presentation may limit its usefulness with certain audiences. As a team, we have learned that the preparation and delivery of all clinical trials education programs need to be carefully attended to by adapting the content, presentation style, and existing resources to address the needs of each particular audience. Although such modifications require creativity, time, and diligence, a presentation customized to the audience will peek and maintain interest and will increase the effectiveness of the overall effort.

Lesson #4: Allow Time and Patience Required to Create “Trust” With Disenfranchised Communities

Once organized educational efforts are implemented within an underrepresented community, it may take 5 or more years before individuals are likely to have sufficient trust, knowledge, and comfort to make informed decisions about enrolling in a clinical trial. Trust does not occur merely because of an endorsement from a respected individual or organization, but rather occurs in demonstrating commitment, consistency, and trustworthiness over time. In developing collaboration with communities, the research team must demonstrate patience since hurrying the process may be counterproductive, leading to further distrust and delays. The team may need to allow the process to unfold over many years. For example, tribal institutional review board approval of some interventions have taken as long as 3 years as a result of the tribe’s previous experience with untrustworthy researchers.

A common misconception among providers is that access to an underrepresented community can be achieved simply by including a respected minority representative (individual or community group member) on the research development team. Just because the minority representative is trusted or accepted within the intended population does not mean their endorsement is sufficient for recruitment. Thus, it should be remembered that it may require many years before a significant increase is seen in the number of Natives who are recruited and retained in clinical trials.

Lesson #5: Learn From Other Ongoing Similar Projects

Concurrent with our development of the “7Cs” and CTENA, was the implementation of the Genetic Education for Native Americans (GENA) curriculum supported by the National Human Genome Research Institute (NHGRI R25 HG01866).³³⁻³⁵ Based on pilot testing, the curriculum was reorganized around objectives. This strategy allowed for tailoring of instruction to the needs of individual groups or organizations. This flexibility greatly increased the GENA workshop effectiveness. Based on evaluations from GENA, a similar format was adopted by the “7Cs” team for both the providers’ curriculum and the CTENA and proved to be equally effective.

Lesson #6: Generate Instruction That Is Interactive and Fun

Since the majority of our customized workshops are implemented during conferences, the participants

can freely leave if the program is not stimulating and can attend another concurrent, session that appears more interesting. Our initial efforts that focused almost solely on didactic presentations were less than satisfying, as were the formats we pretested. The “7Cs” team decided to “dare to be daring” and created activities for providers that were sometimes based on games (eg, Clinical Trials Jeopardy), relied on active group collaboration (eg, reconstructing the cancer timeline), encouraged sharing some of their personal background (eg, “What is your own cultural background and how does it affect your daily interactions with others?”), or used problem solving through small group analysis of case studies based on actual events. Based on pretest/posttest findings and participant comments, the interactive components of the lessons were both enjoyable and proven to be essential to increased learning. We also found that participants experienced a range of emotions during these segments (eg, outrage, humor, passion) that greatly influenced long-term learning and retention of the clinical trials didactic content.

Lesson #7: Assemble a Culturally Diverse Team That Allows for Greater Cultural Depth Throughout the Curriculum

The development team included individuals from diverse cultural and professional backgrounds. For example, 2 members of the team are from medically underserved populations and frequently communicate culturally specific community perspectives. Likewise, 2 other members work with medically underserved communities both regionally and nationally and have found practical ways to address messages that are frequently misunderstood. One has vast experience working with multiple trials and can provide examples from the clinical setting. Another has been the lead recruiter for a large NCI trial and has multiple examples of how medically underserved patients interpret scientific language. A third has a greatly prized ability to translated complex information into easy-to-comprehend phrasing, methods, or examples, and another has experience working with Native American cancer patients and hearing their interpretations of scientific language.

This diversity greatly contributed to the breadth and depth of the culturally relevant information included in the curriculum. In addition to constantly educating and learning from one another, this cultural diversity enriches the content of the curriculum. We frequently found that one of us would make a statement that was not clearly understood by other team members. During the process of explaining or elaborating, we began to provide examples from our

own backgrounds and share the relevance to whatever lesson we were currently studying. These developmental interactions had a great influence on the interactive experiences included in the curricula.

Lesson #8: Write the Curricula as a Team Effort

To benefit from the multicultural experience and areas of expertise of the “7Cs” team, we wrote the curricula together. To do so requires access to an LCD projector (allows the computer image to project on a screen visible to the entire group) and a typist who can quickly load team members’ comments into a word processing program as the ideas are being generated. We project the notes on the screen and all of us work on the same document simultaneously. It has also allowed for variable interpretations of the same phrases, which cues us to cultural or profession-specific connotations for selected phrases. This group effort via the LCD has been fun and productive and has allowed active contributions from all team members. We have also used this process for drafting abstracts, preliminary papers, and grant applications from both the “7Cs” and the CTENA. Working together, we can combine our various areas of creativity and expertise to create a quality product in which we all equally share. We highly recommend this approach to others.

Lesson #9: Dedicate Sufficient Time to Present Workshop Objectives

Clinical trials information is difficult to understand. To allow time for the participants to have information presented to them, as well as to allow time for them to actively interact with the content, each objective requires an average of 45 minutes for implementation. Participants need time to ask questions and obtain clarification about the educational content as well as to share their information and personal stories related to cancer and clinical trials with one another. In addition, when working with Native groups, it is essential to allow enough time for personal introductions of the attendees at the beginning of each workshop. While this is a culturally appropriate use of educational time, the introductions, as well as the time for group interactions, need to be incorporated into the overall presentation time so that the didactic content and interactive activities are not rushed and all content is presented.

Lesson #10: Recognize Culturally Specific History

All healthcare providers and researchers should be aware of the Tuskegee syphilis study and similar clini-

Table 2. — Development of the Curriculum: Challenges and Solutions

Challenge	Solution
Creating a diverse but supportive team	Encouraging open, honest discussions of opinions; building trust in each other and the collaborative process over time
Managing logistics	Being flexible with meeting times and locations; blocking out five hours for each meeting; meeting away from primary work sites to decrease interruptions and distractions
Improving the team's knowledge and understanding of diversity within the Native community	Attending Native community events to learn more about how local people perceived and reacted to different issues; discussing lessons learned and questions generated by experience; identifying how the information could be used to inform the curriculum
Maintaining a tight timeline for curriculum completion	Having one or two team members take the lead on a component or all of a module; circulating the draft module prior to the meeting; working to build consensus about materials to be included; recognizing the time and effort that went into developing the draft
Making complex information understandable	Breaking down concepts into contexts more common to Native communities; refining, pretesting and revising the newly crafted concepts; using each member's knowledge and creativity to create an easy-to-understand, interactive, and culturally respectful curriculum

cal trials experiences that may have occurred with certain minority populations. When presenting clinical trials education to African Americans, the ethical, legal, and social vulgarities of Tuskegee need to be addressed. However, every other medically underserved community has its own “Tuskegee-like” experience. For example, in Indian Country, the community is well aware of unethical research practices. Among the more common informally cited experiences within the community is the forced sterilization of American Indian women without informed consent (GAO Report 1975). This history must be openly acknowledged before we can move further into education or expect any belief or trust in the healthcare system and future participation in studies. Acknowledging these experiences and incorporating information about them into the presentations is essential if barriers related to trust are to be overcome.

Challenges and Solutions

Various challenges were encountered in the process of developing the CTENA curriculum (Table 2). Probably of most importance to the team was the need to learn to work together, respecting each other's background as well as personal and professional knowledge, ideas, and opinions. We learned that different words or phrases (such as “gatekeeper”) had different meanings to some of us (someone who lets one receive care or someone who blocks care) and that each meaning could affect the curriculum in a different manner. We had to learn to share our thoughts and discuss our differences of opinion and then either use the differences as part of a lesson in the curriculum or come to a consensus on the content or context that would be incorporated. Another challenge related to the logistics of meeting together to create the curriculum. Members of the team neither work nor live near each other, and the Colorado environment (eg, blizzards, forest fires, foggy morn-

ings), as well as the need to travel relatively long distances, required flexibility in our meeting times and places. We found that allocating approximately 5 hours for each meeting and working away from primary work settings was beneficial to team collaboration and facilitated curriculum development.

Additional challenges included (1) the need to improve the team's understanding of diversity within the Native community, which was accomplished by attending Native functions and then discussing the lessons learned and questions generated by the experience, (2) the need to maintain a relatively tight timeline for curriculum development, which required forcing ourselves to work consistently and sometimes dividing up the work with 1 or 2 members of the team taking the lead, and (3) the need to learn how to make complex information understandable as well as interesting and fun, which required discussion, continual “wordsmithing,” pretesting and revising, and use of everyone's creativity.

Conclusions

We have described lessons learned while developing a clinical trials education curriculum for intertribal groups of Natives from the North American continent. From these lessons, we offer suggestions for developing clinical trials education curricula for those working with underserved populations. We feel these suggestions are applicable for most researchers working with diverse communities. However, local communities will need to modify their solutions to be culturally respectful to their local communities. In addition, others may find, as we did, that the materials currently available are of limited use when applied to underserved populations; thus, they may desire to revise, develop, or and tailor materials to meet the needs of a specific population.

We found that having a culturally diverse team working together on the curricula in “real time” (ie,

projecting the work via LCD projector while the group wrote and edited) improved both the overall content and the cultural competence of the materials we developed. Given that cancer rates are increasing and survival rates are poor for many underserved populations and also that participation in clinical trials may improve care and survival, educating special populations about cancer clinical trials is essential. However, clinical trial recruitment with a heavy focus on enrollment numbers may lead to the impression in underserved communities that they are a means to an end. Clearly, enrollment goals need to be met. An approach where potential participants are given a foundation of understanding via an unbiased presentation of the purposes of clinical trials and the implications of participation will be more likely to yield the desired result: informed participation of medically underserved populations in clinical trials.

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